Genetic editing with CRISPR/Cas9: A scientific, ethical, and pastoral approach

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A Scientific, Ethical and Pastoral Approach

by

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To all my brothers and sisters in parish ministry,

providing pastoral care to the sick and their caregivers,

especially the priests of the Diocese of Worcester.

Contents

Introduction

In 2018 the movie *Rampage* reached the big screens throughout the nation and the world. The main actor, good guy, and hero is Dwayne "The Rock" Johnson. Like most of his movies, it is filled with action. In this particular script, the villain is not a person or a gang, but three animals–a gorilla, a wolf and an alligator–that mutated to an enormous size and at the same time grew in strength and developed other traits. These creatures destroyed the city of Chicago and everything they found on their way. What happened to them that caused this mutation? It was CRISPR. In a popular non-scientific approach, the story of the movie has CRISPR as the new genetic tool that can cause these incredible changes in the body without any control just by being exposed to it. Unfortunately, some people, when sitting in front of the screen, and watching Hollywood's creations and imagination, process some of the contents as if it was a documentary. In their minds, these films can become the source of truth and learning about science and even theology. This is what I witnessed personally when youth and adults approached me with questions regarding religious beliefs based on movies. Two other vivid examples concerned with what they saw, heard, and then believed as true from the movies are *Stigmata* and *The DaVinci Code*.

Acknowledging the possible misunderstandings of genetic editing, I consider it important and necessary to demystify any trends that canonize or demonize genetic editing, particularly CRISPR/Cas9. To the best of my ability, I discuss what it is and what it is not with the lenses of science and religion.

During the last hundred years, scientific research has become even more fascinating and daring than before, because it has been able to literally reach into what was considered part of the unseen world. The knowledge about the human body and its genetic constitution greatly increased. The fact that scientists can now determine the information related to what is considered to be the healthy condition for a person, allows them to approach illnesses from a different point of view. For the longest time, illnesses were treated exclusively with medicines that could overcome diseases, or in some cases only slow them down and prevent them from getting worse. Medicines were found in nature and more recently created and produced in a lab. In research labs, the newer approaches imply discovering illnesses and remedies that are genetically based. More and more, the focus is on structural damage and repair. The hope of researchers is to obtain results that are long term and truly effective in restoring or assuring the good health of the individual.

Genetic editing treatments are for genetic illnesses and conditions. The following are some examples of which diseases could be targeted and which cannot be targets for research.

Genetic illnesses:	Non-genetic illnesses:
Cystic fibrosis	Kidney failure
Sickle cell anemia	AIDS
Huntington's disease	Tuberculosis
Coronary artery disease	Cirrhosis
Breast cancer	Lung cancer
Down syndrome	

Within genetic illnesses there are different categories. An overarching category is whether the disease depends on a single gene mutation or various mutations in different genes. Clearly, the number of mutations and locations will determine how difficult or realistic it will be to try to correct them. Moreover, it is necessary to assess whether the mutation is the direct cause of the illness or if it predisposes to it or increases the risk to suffer from the disease. In the field of genetics, the more scientific research is done, the more connections researchers find between a certain illness and its genetic etiology. In some cases, the person is born with a mutation, in others the exposure to things in the environment caused the mutation. And as I mentioned earlier, in many situations it is the actual genetic makeup of the individual that makes the person more susceptible to contracting a certain disease.

Moreover, we need to acknowledge the shift in services and goods provided. For the longest time in human history, the economy aimed at providing external goods to people. These goods, these objects were changing and improving. Notice for example, the ongoing modification of cars to make them more efficient and comfortable, with more accessories and safer for the passengers. In the last couple of centuries, technology is still looking to make 'things' faster, smaller or stronger, but at the same time it searched for ways to improve the actual human body. The latter can be seen in the prevention of illnesses (vaccination), providing healing from a condition (pacemaker), supplying artifacts to overcome a handicap (prosthesis) or changing a 'defect' (corrective surgery). The next step of these improvements seems to be the human body itself.

Our present Western philosophy of life and our understanding of the human body are too complex to be narrowed into one general concept. As we look back, what can be highlighted are two events that greatly influenced genetic experimentation. The first one is the theory of

evolution which acknowledges that the living species survive and strive by experiencing naturally an ongoing modification and adaptation. Because these changes are considered to be random acts of nature, of which we have no control, there is an acceptance of the final results. The second event is the post Enlightment, with its emphasis on the individuality of the person. Previously, some societies focused only on the tribal needs; it was a collective approach. Other societies attended only to the aristocrats and those in position of power, while others in the community had no voice and no rights. In this post Enlightment era there has been a greater focus on the individual's rights and autonomy.[1]

Maybe due to the influence of science fiction movies or just the lack of scientific knowledge, some people are opposed to anything that tampers the human genes, or any other gene. Besides fear of the unknown, some religious values prohibit any tampering of the body, even in the case of blood transfusion. Other people are inspired by the spirit of consumerism and innovation and are quickly receptive to anything new, but often they do not know what are the actual implications and long-term effects of many changes. We can see this struggle for consumption every day. Some people do not mind eating 'genetically modified' products because of their lower cost, while others are demanding that their products be 'organic'.

This thesis studies genetic editing by focusing on the technique, its possible uses, and its moral implications. Even though I am a science lover, it took me some extra time to truly grasp what is gene editing. Therefore, on the one hand, one of my objectives is to illustrate what gene editing is in the simplest way. The scientific contents cannot be omitted from the discussion if we are about to make a conscientious judgment; it is part of being well informed. On the other

[1] See Nikolaos Koios, "Theological Anthropology and Human Germ-Line Intervention," *Christian Bioethics* 18, no. 2 (2012): 189.

hand, this is a thesis in theology and not a scientific dissertation; therefore it will not go into profound depth to examine techniques and illnesses.

In our world, where so much is happening in genetics, this paper is focusing on genetic editing, particularly the technique of CRISPR/Cas9. Genetic editing is the technique that allows to add, delete, or alter a gene. The genes hold the genetic information of the organism, and provide all the instructions regarding the tissues, the organs, and finally the body. Editing is different from gene therapy; the former is changing a segment within the gene, and the latter is an actual insertion of a new and healthy gene into the organism.[2] Researchers of both techniques are aiming at clinical trials; so far the gene editing is not fully approved by the US FDA.[3]

Genetic editing, as with almost all other research, began with other organisms such as plants and animals. The key question that scientists are asking is: could genetic editing become the yet missing treatment to heal or prevent certain diseases or disabilities that so far have no therapy?

Several techniques for gene editing have been created, among them meganucleases, Ztns, and TALENs. But in the last few years, the scientific world has shown great excitement (and hope) with CRISPR/Cas9. Because of its expected precision and efficiency, and because it is a less expensive technique, it may be the best success story in genetic research at the present time.

What determines the power of one genome editing technique over the other? What would make it a success story? The ideal technique could be applied to any cell of the organism. It should be precise in targeting a section of the gene. It is expected to be efficient /reliable in finding the target by leaving no traces of a foreign DNA and simple to replicate in any lab and

[2] See National Academy of Sciences, Engineering, and Medicine, *Human Genome Editing: Science, Ethics, and Governance* (Washington, D.C.: The National Academy Press, 2017), 12.
[3] See ibid., 13.

therefore cost effective.[4] CRIPR/Cas9 seems to have all those advantages. Some call it the "perfect molecular scissors." [5]

Scientists have been able to recognize over 7,000 monogenetic disorders. These phenotype 'imperfections' are for the most part harmless.[6] The point is that it is common for a person to have genetic defects. Some of the consequences of these defects can be addressed with drugs. What is problematic is when they are not that easy to correct.

Moral theology holds in a prime position the role of conscience in the decision making of the individual. It is there where persons encounter the spirit of God that guides them. No moral agents should go against their conscience. The primacy of the conscience is based on being well formed and properly educated. Persons should take advantage of many resources, written or verbal, to enlighten their understanding on specific issues. But also there is a need to pray asking for the assistance of the gifts of the Holy Spirit. Therefore, in these pages I look deeper into the human body to grasp the creative power we have received by being made in the image and likeness of God, praying for divine wisdom in order to make not just good decisions but the best moral decisions for our own selves, and also for all our brothers and sisters.

Unfortunately, within all levels of education people believe that the Catholic Church is against any scientific progress. The Congregation of the Doctrine of the Faith, in the instruction *Dignitas personae: On Certain Bioethical Questions,* reminds the world that the Church's Magisterium does not take an antagonistic position towards science. In appreciation of scientific achievements, the Magisterium insists in keeping a balance within genetic research. On the one hand, it is important to encourage and to support scientific research because it allows to improve

[4] See John Parrington, *Redesigning Life: How Genome Editing will Transform the World* (Oxford: Oxford University Press, 2016), 83.
[5] See ibid., 84.
[6] See Philip R. Reilly, *Orphan: The Quest to Save Children with Rare Genetic Disorders* (Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 2015), 281.

the quality of human life.[7] On the other hand, the community must be cautious and assess wether this research is truly opened to all peoples and respects the dignity of every person. Our human history has shown great accomplishments by conquering illnesses and discovering drugs and treatments. But our history has also shown terrible abuses suffered by races, groups, ages and in various stages of life for the sake of science. Hence, "The introduction of discrimination with regard to human dignity based on biological, psychological, or educational development, or based on health-related criteria, must be excluded."[8]

Pope Benedict XVI, in his encyclical letter *Caritas in veritate* reminds the entire world, believers and non-believers, of the interconnectedness between truth and charity. One impacts the other and, in particular, searching for scientific truths charity should prevail.

> Technology enables us to exercise dominion over matter, to reduce risks, to save labour, to improve our conditions of life. It touches the heart of the vocation of human labour: in technology, seen as the product of his genius, man recognizes himself and forges his own humanity. Technology is the objective side of human action whose origin and *raison d'etre* is found in the subjective element: the worker himself. For this reason, technology is never merely technology. It reveals man and his aspirations towards development, it expresses the inner tension that impels him gradually to overcome material limitations. *Technology, in this sense, is a response to God's command to till and to keep the land* (cf. Gen 2:15) that he has entrusted to humanity, and it must serve to reinforce the covenant between human beings and the environment, a covenant that should mirror God's creative love.[9]

For those in seminaries and parishes, labs and hospitals we should remind "that moral evaluation and scientific research must go hand in hand, and that charity must animate them in a harmonious interdisciplinary whole, marked by unity and distinction."[10]

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[7] See Congregation for the Doctrine of the Faith, *Dignitas personae: On Certain Bioethical Questions,* (2008), no. 3.
[8] Ibid., no. 8.
[9] Benedict XVI, *Caritas in veritate* (2009), no. 69.
[10] Ibid., no. 31.

Chapter

CRISPR/Cas9 and somatic illnesses

Our journey takes us deep into the human body, into the cells, into the chromosomes where we find the genes. Genes are the information map of the organism and they are present in every cell. The genes are formed by the DNA which is a double helix that consists of a sequence of nucleotides and those sequences define a characteristic or function of the cell. Nucleotides are the basic units of the DNA, and there are four different ones: Adenine (A), Cytosine (C), Guanine (G) and Thymine (T). They bond to each other as pairs, limited to an A-T and G-C combination. Once they are lined up they create the double helix. Figure 1 shows the location of the DNA within the cell.

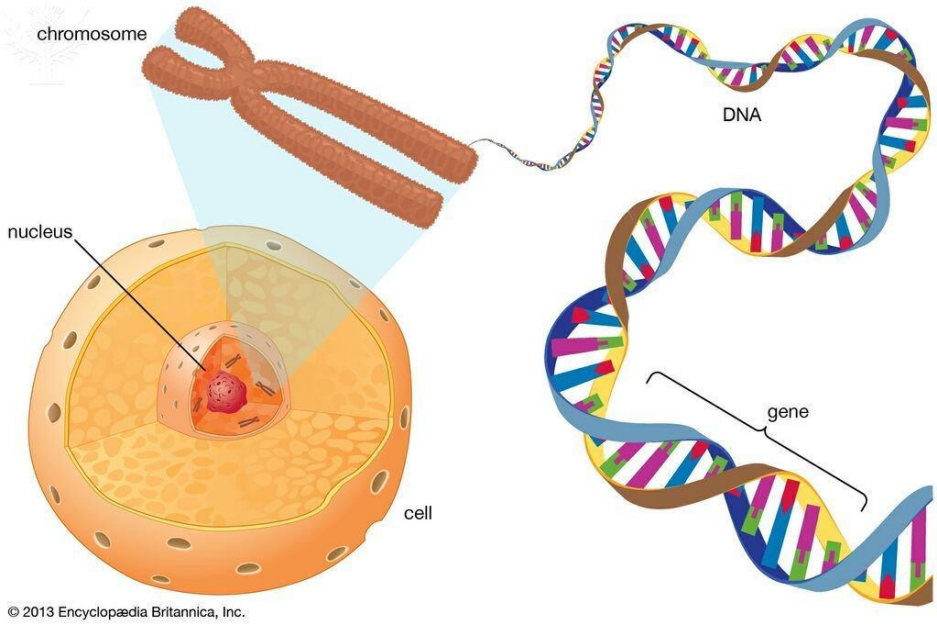

Figure 1. Location of the DNA.[11]

The expression of the information code within the DNA is accomplished by the RNA.[12] The RNA is a nucleotide polymer that copies the sequences of A, C, G and T from the DNA and translates those codes in order to produce proteins. Proteins are polymers made of a combination of 20 different aminoacids, in contrast to the RNA that is formed by the combination of only four bases. The proteins contribute to cell functioning and cells form the different organs and tissues of the whole body. This entire map or set of instructions on how to build up the body is called the human genome. Presently the human genome is estimated to contain three billion pair bases that can be translated into approximately 20,000 proteins.[13] Figure 2 shows the difference and similarity between the DNA and RNA.

[11] Britannica Learn, last accessed October 28, 2019, https://twitter.com/britannicalearn/status/789510420197408768?lang=en.

[12] "Ribonucleic acid (RNA) is a molecule similar to DNA. Unlike DNA, RNA is single-stranded. An RNA strand has a backbone made of alternating sugar (ribose) and phosphate groups. Attached to each sugar is one of four bases– adenine (A), uracil (U), cytosine (C), or guanine (G). Different types of RNA exist in the cell: messenger RNA (mRNA), ribosomal RNA (rRNA), and transfer RNA (tRNA). More recently, some small RNAs have been found to be involved in regulating gene expression. https://www.genome.gov/genetics-glossary/RNA-Ribonucleic-Acid.

[13] See National Academy, *Human Genome Editing,* 62.

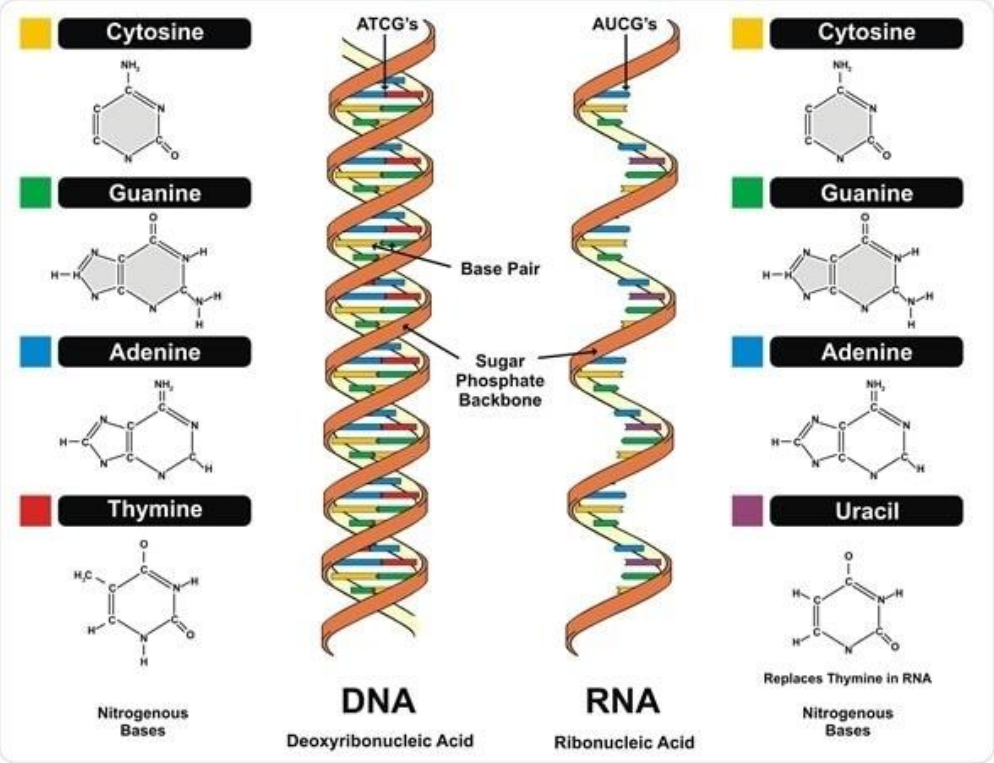

Figure 2. DNA versus RNA.[14]

A mutation is a change in the expected sequence of the nucleotides within a particular DNA. They "can occur spontaneously during cell division or can be triggered by environmental stresses, such as sunlight, radiation, and chemicals".[15] These mutations can remain unnoticed throughout the life of the person, because they are harmless; or they can express themselves in a physical trait or condition.

Therefore if the goal is to influence the body, a specific organ or function within the body, then one alternative is to go into the core, right to the genes. At the present time, CRISPR/Cas9 is considered one of the most effective ways of bringing about the change needed. Cas9 (which stands for ***C***RISPR ***as***sociated protein ***9***) is a nuclease, which means that it is a protein that can cut the DNA or RNA. Once a scenario for editing is chosen, Cas9 attaches to

[14] DNA versus RNA, last accessed October 28, 2019, https://i2.wp.com/sciencesamhita.com/wp-content/uploads/2016/03/dna-versus-rna.jpg?resize=672%2C372&ssl=1.
[15] National Academy, *Human Genome Editing*, 302.

the targeted DNA and cuts the segment of desired nucleotides. When a segment is cut off, there are two main possibilities: one is that the two loose ends can reattach to each other (nonhomologous end joining, NHEJ);[16] and the other is that a new segment with a new sequence of nucleotides can be added (homology-directed repair, HDR).[17] If it is left to the DNA to repair itself, there is always the possibility of creating a new sequence, which could cause a new mutation and even disable the gene. Therefore, to avoid negative or unhealthy results, the preferred option is to add a strand of RNA (half of the helix) with the desired or healthier sequence. Once this RNA is in place, it will be completed naturally with the corresponding nucleotides to form the double helix.[18]

Human proteins are produced within the cells, but Cas9 was originally found and produced in bacteria. The actual technique of gene editing is called CRISPR/Cas9. The name comes from ***c***lustered ***r***egularly ***i***nterspaced ***s***hort ***p***alindromic ***r***epeats. It refers to short, repeated segments of DNA originally discovered in bacteria.[19] The most commonly used and preferred CRISPR/Cas9 combination comes from the bacterium *Streptococcus pyogenes*. Why bacteria? Scientists learned from the bacteria that in order to protect themselves, they take segments of the DNA from their invaders and integrate them into their own genome. This allows them to be prepared with a defense system that can cleavage another attack of the invading phage. The new segment of DNA, which is usually 20 to 50 nucleotides long, is incorporated into the gene of the bacteria leaving its original DNA spaced in between the new segments and with a similar length. This pattern of incorporating and spacing is what gave this method its name.[20]

[16] See National Academy, *Human Genome Editing*, 63.
[17] See ibid., 64.
[18] See ibid., 2.
[19] See ibid., 2.
[20] See Kursad Turksen, ed., *Genome Editing* (Switzerland: Springer, 2016), 6.

The actual method of editing with CRISPR/Cas9 involves that the nuclease is combined with a strand of RNA containing the desired sequence of A, C, G, T targeted for removal. This RNA is created in the laboratory for this specific purpose and it leads the CRISPR/Cas9 to the target in the DNA. Due to this role, it is called guide RNA (gRNA). Once it reaches the desired sequence it cuts off that segment of DNA. Immediately it replaces it with a new segment of RNA, with new coding information. Figure 3 is a simple illustration of how does CRISPR/Cas9 interact with the DNA.

Advantages of CRISPR-Cas9 compared with other genetic editing methods

When comparing it with other methods of genome editing, all the scientific journals recognize that at the present moment CRISPR/Cas9 is the best option. "The CRISPR/Cas9 system is simpler, faster, and cheaper relative to earlier methods and can be highly efficient."[21] With the other techniques a new protein has to be created or engineered to match for each genome. With this method the protein that is always used is Cas9. What needs to be created is the guide RNA (gRNA), and that usually takes only a few days, it is simple to do and can match any sequence of nucleotides. In comparison with other methods of editing, the preparation process went from $5,000 USD for a previous method called ZFNs (zinc finger nuclease) to $30 USD for Cas9/gRNA.[22] Clearly a dramatic reduction in cost! The production of a variety of gRNA in contrast to a variety of proteins is the key difference between these methods.

[21] National Academy, *Human Genome Editing*, 65.
[22] See Parrington, *Redesigning Life*, 93.

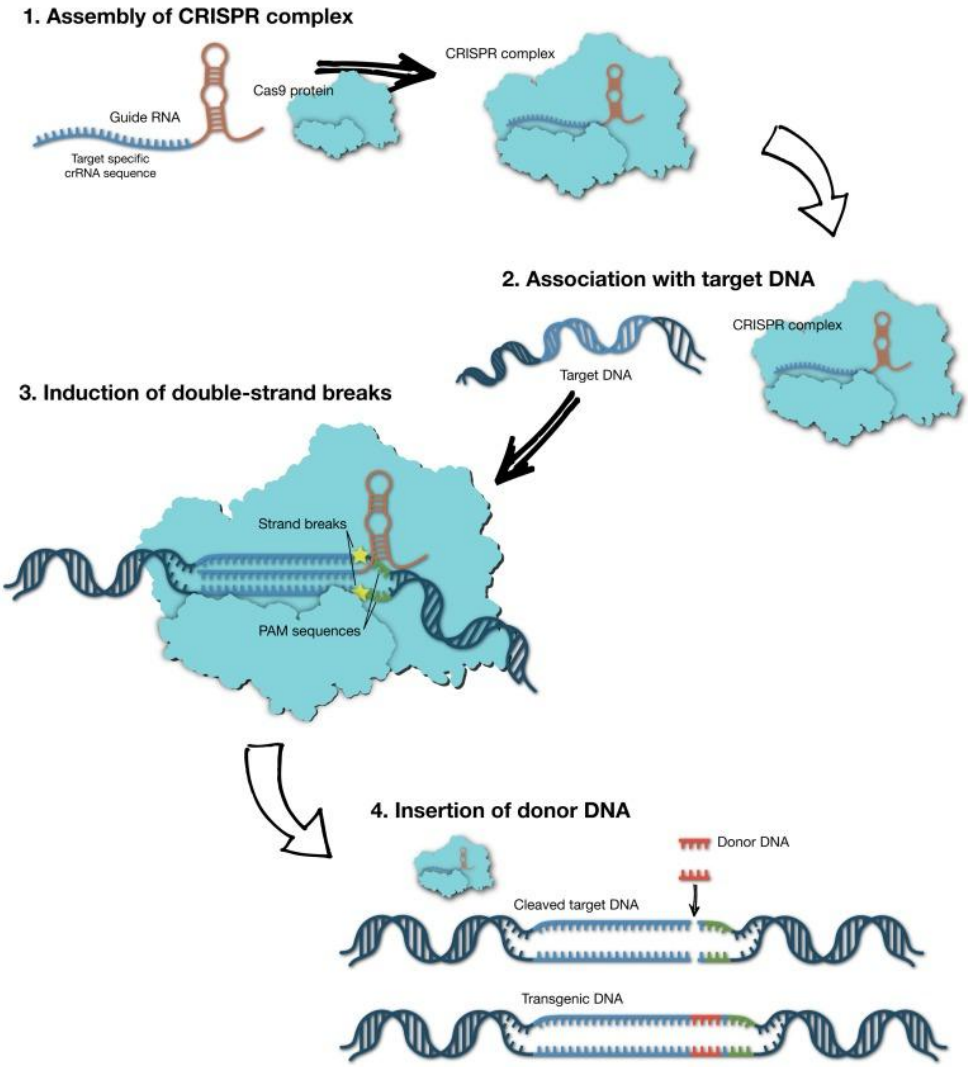

Figure 3. Mechanism of CRISPR/Cas9.[23]

Some of the advantages of CRISPR/Cas9 highlighted by the scientific world can be summarized as: this endonuclease is constant and does not need to be reengineered for each target; it can target multiple sites simultaneously; it has been used in vitro and in vivo (other methods of genome editing can only be applied in vitro); it has a great ability to cleave the DNA

[23] Mechanism of CRISPR/Cas 9, last accessed October 28, 2019, https://www.ncbi.nlm.nih.gov/books/NBK464635/figure/gen_edit.F2/?report=objectonly. Copyright Notice: All Assay Guidance Manual content, except where otherwise noted, is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 3.0 Unported license (CC BY-NC-SA 3.0), which permits copying, distribution, transmission, and adaptation of the work, provided the original work is properly cited and not used for commercial purposes.

in spite of being an external agent (epigenetic).[24] In other words, compared with the previous discovered techniques, CRISPR-Cas9 has simple reprogramming, a highly efficient and multiple capability.[25] This method can be applied to multiple genes at the same time.

Research and experimentation

For several years and with great success, gene editing experimentation has been applied on yeast, zebrafish, mice, rats, rabbits, monkeys, and a variety of crops and livestock. Overall the purpose was to make these crops and livestock resistant to certain pathogens, to protect them from diseases and parasites and also to increase their productivity. The advantage highlighted is that it would eliminate the need of using pesticides and other chemicals which could cause secondary impacts on the environment.[26] During the last few decades some experimentation with livestock has been done with the special interest of making the proper modifications that would create the right match for xenotransplantation, i.e. the transplantation of organs or tissues between different species, with a special interest in obtaining healthy anatomic material from an animal for a human being. Moreover, other attempts to modify certain tissues in these animals have been done so that they can become models for trials of research on human diseases.[27]

More recently, basic research has taken place on somatic cells, such as human skin, liver and heart.[28] In order to achieve a recognizable impact, labs have been using HeLa cells and mice as critical research subjects for observation of the effectiveness of genome editing.[29] Especially

[24] See Turksen, *Genome Editing*, 8.
[25] See ibid., 2.
[26] See Isabelle Duroux-Richard, Carine Giovabbabgeli and Florence Apparailly, "CRISPR-Cas9: A revolution in genome editing in rheumatic diseases," *Joint Bone Spine* 84 (2017): 3.
[27] See Turksen, *Genome Editing*, 16.
[28] See National Academy, *Human Genome Editing*, 3.
[29] See Parrington, *Redesigning Life*, 94-95.

in vitro, most cells have a limited reproduction timeline before they die. The HeLa cells, which were 'discovered' in 1941, have been dividing and multiplying themselves since then.[30]

Based on the published research, when it comes to experimentation with human cells and illnesses, some researchers focused on embryonic stem cells. For other researchers, the goal, as in the case of other living creatures especially the mice, would be to apply the editing method to the full grown animal. Ultimately, the goal of the research is to benefit adult human beings, to edit their genes.[31]

Even though clinical trials with humans are not yet allowed, in April 2015 it has been announced an experimentation with human embryos. Junjiu Huang was the leader of a team at Sun Yat-Sen University in China that tried to correct a blood disorder called β-thalassaemia. The research was not considered fully successful due to a low efficiency and accuracy and because of secondary effects. Other scientists believe that the unsuccessful outcome was caused by not using the best CRISPR/Cas9 technology.[32]

In the United States, scientists are already using CRISPR/Cas9 with human genes:

> On August 2, 2017, Shoukhrat Mitalipov's research lab at Oregon Health and Science University in Portland published their results on the editing of DNA in human embryos, the first known attempt in the United States. The Mitalipov lab set out to correct the mutated MYBPC3 gene in human embryos, which often causes a condition called hypertrophic cardiomyopathy, characterized by abnormally thick heart muscles. The authors stated that this condition is "the commonest cause of sudden death in otherwise healthy young athletes."[33]

Another attempt with human trials took place in China in November 2018. Dr. He Jiankui announced in Hong Kong,

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[30] In her book, *The Immortal Life of Henrietta Lacks,* Rebecca Skloot explains the 'ongoing life' of the cancer cells named HeLa.
[31] See Parrington, *Redesigning Life*, 99.
[32] See ibid., 107.
[33] James Mary Ritch, O.P., "Human Gene Editing: A Century of Tears to a Century of Fears?," *Dominicana* (August 29, 2017), last accessed 11/18/19, https://www.dominicanajournal.org/human-gene-editing-a-century-of-tears-to-a-century-of-fears/.

> that he had recruited several couples in which the man had H.I.V. and then used in vitro fertilization to create human embryos that were resistant to the virus that causes AIDS. He said he did it by directing Crispr-Cas9 to deliberately disable a gene, known as CCR_5, that is used to make a protein H.I.V. needs to enter cells. Dr. He said the experiment worked for a couple whose twin girls were born in November. He said there were no adverse effects on other genes.[34]

This news provoked mixed reactions within the scientific circles in China and beyond.

Before actually moving forward to human trials the scientific community, but also the general population, should be made aware and educated in this matter. This education is essential, because there is already a shift in support from the general community even without necessarily knowing and understanding the benefits and adverse effects behind this editing technique. Possible future clinical applications should not depend on human consensus, especially if it is not well informed.[35]

The first challenge for researchers is trying to identify if (and which) diseases can actually be approached and healed with genetic editing. One of the concerns is that a gene causing a disease may handle several traits of the person, therefore changing or editing the gene may have other impacts beyond the desired healing. Based on the experimentation with mice, CRISPR/Cas9 may be able to edit the genetic mutations causing muscular dystrophy. The trials focused on cardiac and skeleton muscles of the mice. The results did not indicate a complete restoration but there were enough genetic changes to physically observe an improvement in the mouse's movement.[36]

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[34] Gina Kolata, Sui-Lee Wee, and PamBelluck, "Chinese Scientist Claims to Use Crispr to Make First Genetically Edited Babies," *The New York Times*, November 26, 2018, https://www.nytimes.com/2018/11/26/health/gene-editing-babies-china.html.
[35] See Sandy S.C. Hung et al., "Genome engineering in ophthalmology: Application of CRISPR/Cas9 to the treatment of eye disease," *Progress in Retinal and Eye Research* 53 (2016), 15.
[36] See David A. Prentice, "Science," *The National Catholic Bioethics Quarterly* 18, no. 2 (Summer 2018), 332.

Which human somatic illnesses could be treated?

Somatic cells are the cells found in the body except for the reproductive cells (egg and sperm) and their precursors.[37] Figure 4 shows the 22 pairs of somatic chromosomes and the one pair of sex chromosomes.

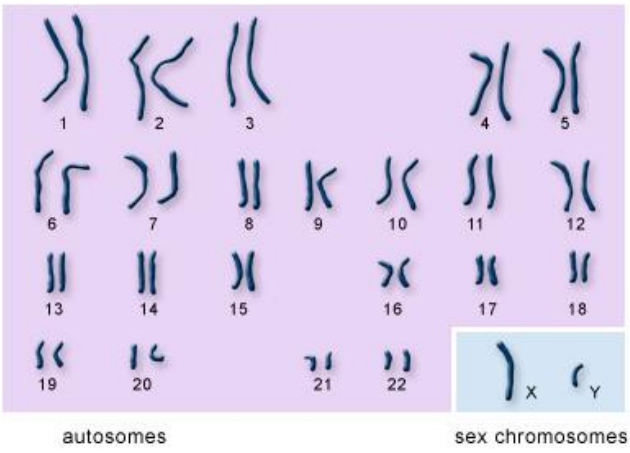

Figure 4. Human chromosomes.[38]

Which somatic illnesses have a genetic cause? Among the illnesses caused by a mutation in the aminoacid sequence of the person are sickle cell disease, hemophilia A & B, some forms of Duchenne muscular dystrophy (as mentioned earlier, it has already been tried with mice), Wiskott-Aldrich syndrome, and cystic fibrosis.[39] At the same time, successful trials have taken place by genetically inactivating viral infections that attack the body. All of these illnesses are the result of some form of genetic mutation within the carrier, that can be either inherited or not. Therefore, it seems that this method of gene editing could not be used to heal what are considered non-genetic illnesses such as heart diseases and diabetes, because their causes go beyond the genetic issues.

[37] See National Academy, *Human Genome Editing*, 5.
[38] Human chromosomes, U.S. National Library of Medicine, last accessed October 28, 2019, https://ghr.nlm.nih.gov/primer/basics/howmanychromosomes.
[39] See Turksen, *Genome Editing*, 16.

However, genome editing could be clinically applied to these complex somatic illnesses by removing the affected cells from the body, performing the genetic editing and then returning these cells to the body. Since this procedure would take place outside of the body (*ex vivo*), it would be easier for the lab personnel to confirm the success or failure of the editing. It could also be possible to apply genetic editing *in vivo* but it would involve more technical challenges.[40] Right now it is all theory when it comes to clinical applications in human beings. Another important factor that needs to be determined is whether there is an ideal stage or age of the patient to make this procedure successful; or if there is threshold beyond which it would be too late to proceed. Maybe due to the lack of human trials it is not possible to answer those questions at this time.

The less complex is the mutation, the more effective is the editing process. One human related condition, that could be appropriate for research, concerns the genes responsible of inflammations and other bone issues causing rheumatic disease. As far as researches know, these diseases are the results of single mutations and therefore a better target for CRISPR/Cas9.[41] Inherited retinal diseases could be another first attempt for using CRISPR in human trials. The eye provides an easy access and a compartmentalized anatomy that increases the success of the editing. Some scientists recommend the eye as the appropriate first clinical trials because human editing can take place *in vivo, ex vivo*, or *in vitro*; and it is focused on 'adult' patients. The downfall remains the same as with all other implementations: there is a percent of the DNA that will restore itself and not necessarily be modified to the desired genetic sequence.[42] In theory, there is no way of achieving a 100% correction and there could be maybe as much as 40% that

[40] See National Academy, *Human Genome Editing*, 5.
[41] See Duroux-Richard et al., "CRISPR-Cas9," 3.
[42] See Hung et al., "Genome engineering in ophthalmology," 11.

will recombine on its own. Therefore the practical option would be to edit as many genes as possible to be able to generate the desired change.[43]

In order to increase the trust that this method could work and therefore human clinical experimentation can begin, there are a few hurdles in the procedure that should be addressed. First, there should be a reduction in NHEJ, which is the nonhomologous end joining, when the DNA reconnects itself. Second, it is necessary to enhance the effectiveness of the HDR, the homology-directed repair, which is the desired new/healthy sequence. Third, improved vectors should direct the CRISPR/Cas9 to the right part of the body and within the cells.[44]

Ex vivo versus in vivo editing

In the everyday work in the world of science, genes carrying only certain diseases can be effectively edited. Some of the cells containing the mutated genes can be removed from the body and edited in a laboratory–*ex vivo*; while other cells would have to remain in the body–*in vivo*. *Ex vivo* editing could be applied to genes contained blood and skin cells and in some neurons; *in vivo* editing could focus on muscles and liver cells and neurons from the central nervous system.[45] In either scenario, the chosen cells must have stem cell-like characteristics, which implies that they can continue to reproduce themselves. When the targeted cells are removed from the body, their genes are edited, and they can be checked several times before they are transplanted back to the body. The challenge in the lab is to isolate the desired cells and being able to grow them outside the body. When *in vivo*, the greatest challenge is improving the targeting, so that no other genes and tissues are being affected.[46] Therefore the key advantages

[43] See Hung et al., "Genome engineering in ophthalmology," 12.
[44] See ibid., 16.
[45] See National Academy, *Human Genome Editing*, 96.
[46] See ibid., 96.

of *ex vivo* are that no other cells are being impacted by the editing process, the genes returned to the body can be selected, and their editing confirmed.[47]

The risks of *ex vivo* could be "apoptosis (cell death), differentiation (changing cell type), cell senescence (aging) and replicative arrest (cells stop dividing)".[48] Besides those risks there are also the challenges of guaranteeing that there are enough healthy genes to be transplanted back to the body and that they are mature or stable enough. If that is not the case, the transplantation could cause new mutations.

The main challenge with *in vivo* is controlling the editing tools. What will they impact once they are inside the cell? Researchers are still working in finding ways to limit the editing to the desired targets, especially to avoid affecting the germ cells.[49] Based on research made on the human genome, the researchers know that in cells there is already a certain level of natural mutations happening that do not cause a major impact on bodily functions. These mutations are caused by radiation and chemicals in the environment. The body copes with these mutations. Recognizing that it is impossible to control 100 percent the impact of the editing tools, a goal is that the off-target mutations are at a lower rate than the natural mutations the body is already facing.[50] It is important to acknowledge than in the preclinical research the ratio between on-target versus off-target is what will determine the efficiency of the method.[51]

The role of government agencies

When it comes to animals and plants the USDA (United States Department of Agriculture) regulates the experiments and the actual implementation of the final results.

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[47] See National Academy, *Human Genome Editing*, 97.
[48] Ibid., 97.
[49] See ibid., 98.
[50] See ibid., 100.
[51] See ibid., 102.

Genetic editing has been placed under the umbrella of genetic therapies and it is the US Food and Drug Administration (FDA) that approves or not the clinical trials. Two are the main concerns for the research. First, there needs to be clarity of the source of the tissue that is to be used for experimentation. There is a difference if the tissue is the 'leftover of a surgery', that is, tissue that would be discarded and therefore not identifiable; in contrast with tissue taken from the person with the purpose of being studied, making that person an actual subject of research. Once the person is a subject, there needs to be an informed consent, because the person needs to be fully aware of what is the purpose of the research and its possible outcomes. The researchers should always obtain the permission of the person to use their biological material.[52] Second, it needs to be clear whether the donors are being paid; because if they are, it is necessary to confirm the absence of conflicts, interests, and abuses. Third, there is also a concern for the safety of the workers involved in the research. As with any other work dealing with biochemistry, it is important to take all the proper precautions necessary in regards to the workers being exposed to and handling the different products and byproducts of the research.

As with gene therapies, the final authority of approval is the FDA. This government agency relies on the support of various committees and boards (the RAC, IRBs, IBCs, among many others). The Recombinant DNA Advisory Committee (RAC) oversees the potential use or misuse of recombinant DNA. In particular: "The Recombinant DNA Advisory Committee is a federal advisory committee that provides recommendations to the NIH Director related to basic and clinical research involving recombinant or synthetic nucleic acid molecules. RAC proceedings and reports are posted to the OSP Website to enhance their accessibility to the

[52] See National Academy, *Human Genome Editing*, 38.

scientific and lay public."[53] This committee is formed by scientists and clinicians, ethicists and theologians, but not government employees. One of its strengths and goals is to make the information accessible to the public, which includes the broader scientific world, but also the common folk. By doing the latter, the purpose is to create a level of trust by educating and informing the citizens.

The individual research labs should have an institutional review board (IRB), which observes the recruitment process of the subjects for the clinical study. As mentioned before it is necessary that the subject is well informed and educated on the research, and has full capacity and freedom to consent.

The labs should also have an institutional biosafety committee (IBC) to guarantee the safe conditions of what is done, who is doing it, and any possible risk.[54] Examples of public venues of information can be found in the Office of Science Policy website and the *ClinicalTrials.gov* website. Once the FDA approves the clinical trials and if the time will come to approve the clinical use of genetic editing, this agency will continue to monitor it in case some delayed negative effects appear.[55]

In December 2016, the *21st Century Cures Act* was approved by Congress to allow genome editing to enter into a fast track if it qualifies as a 'regenerative-medicine therapy'. The expectation is to "facilitate the development, review, and approval of genetically targeted drugs and variant protein targeted drugs to address an unmet medical need in one or more patient subgroups, including subgroups of patients with different mutations of a gene, with respect to

[53] At the National Institutes of Health, the Office of Science Policy describes itself as: "The NIH Office of Science Policy (OSP) promotes progress in the biomedical research enterprise through the development of sound and comprehensive policies. OSP also is the primary policy adviser to the NIH Director on matters of significance to the agency, the research community, and the public." https://osp.od.nih.gov/biotechnology/recombinant-dna-advisory-committee/.
[54] See National Academy, *Human Genome Editing,* 48.
[55] See ibid., 54.

rare diseases or conditions that are serious or life-threatening".[56] If researchers can prove that they are doing this, the FDA could grant them the permission they need to begin the clinical trials.[57]

In the U.S., genome editing research is framed by some general principles or guidelines established by the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research. First, its intention and purpose should be ***promoting well-being***, which includes minimizing any risk in early clinical trials and treatments.[58] Second, to be ***transparent*** with the information to government agencies, other scientists and the public in general, especially those involved in trials. Third, having ***due care*** for the patients by implementing methods of editing once there is enough information to be sure that it is safe to apply editing to humans. The fourth principle is ***responsible science***, which implies the highest standards of research.[59] The fifth principle is critical within and beyond the laboratory, ***respect for persons***. Respect implies always being aware that the person treated has dignity; and that dignity is both individual and collective. Sometimes it is easy for an individual to be lost or unnoticed, becoming then a victim or guinea pig of the scientists; even at times painted as a hero or a sacrificial lamb on behalf of the good of the entire humanity. Also it is important to uphold the dignity of the different groups or categories of people: the sick, the poor, the mentally challenged, the prisoners, just to mention a few of those who have already been used and abused. Sixth is the principle of ***fairness***, which "requires that like cases be treated alike, and that risks

[56] US Congress, *21st Century Cures Act*, Public Law 114-255, Section 3012, last accessed 11/18/19, https://www.govinfo.gov/content/pkg/PLAW-114publ255/pdf/PLAW-114publ255.pdf.
[57] See National Academy, *Human Genome Editing,* 56.
[58] See ibid., 32.
[59] See ibid., 33.

and benefits be equitably distributed."[60] Finally, there needs to be transnational cooperation. In an ideal world, these principles and benefits should apply to anyone anywhere in this planet.

The *Universal Declaration of Bioethics and Human Rights* reminds the scientific world that "a person's identity includes biological, psychological, social, cultural and spiritual dimensions."[61] Unfortunately, our history has proven that many unethical experiments have taken place on indigenous communities and vulnerable people. That is why the developing countries should share the benefits of the medical, scientific and technological research (Art. 2.f). Moreover, the dignity of the person has priority over the interests of science (Art. 3.2). Finally, the subject should be a beneficiary of the research but

> (r)esearch which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection of the individual's human rights. (Art. 7.b).

If the research is conducted by an out of State institution, both the host country and the country of origin should review all the procedures to guarantee the well being of all the subjects involved in the clinical trials (Art. 21). This implies also that all States involved should guarantee that the illicit traffic of genetic-related materials is not taking place.

The person involved in clinical trials deserves the highest level of protection and care. That is why providing the person with as much information as possible is necessary in order for him or her to give their consent. The US Department of Health and Human Services (HHS) has

[60] National Academy, *Human Genome Editing*, 34.
[61] See UNESCO, "Universal Declaration on Bioethics and Human Rights" (October 19, 2005), Introduction. http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/.

regulations for obtaining the subject's consent. These can be found in the *Federal Policy for the Protection of Human Subjects* as it appears in the January 19, 2017 edition:[62]

> Basic elements of informed consent (…):
> (1) A statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures that are experimental;
> (2) A description of any reasonably foreseeable risks or discomforts to the subject;
> (3) A description of any benefits to the subject or to others that may reasonably be expected from the research;
> (4) A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject;
> (5) A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;
> (6) For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained;
> (7) An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a research-related injury to the subject;
> (8) A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits…
>
> Additional elements of informed consent:
> (3) Any additional costs to the subject that may result from participation in the research;
> (5) A statement that significant new findings developed during the course of the research that may relate to the subject's willingness to continue participation will be provided to the subject;
> (7) A statement that the subject's biospecimens (even if identifiers are removed) may be used for commercial profit and whether the subject will or will not share in this commercial profit;
> (9) For research involving biospecimens, whether the research will (if known) or might include whole genome sequencing (i.e., sequencing of a human germline or somatic specimen with the intent to generate the genome or exome sequence of that specimen).

[62] "Federal Policy for the Protection of Human Subjects," *Federal Register* 82, no. 12 (January 19, 2017), 7266.

Ethical issues

Human beings have been blessed with the ability to develop and create techniques that could heal the body. Clearly in the case of somatic illnesses, CRISPR/Cas9 could provide an opportunity to correct a mutation in order to overcome an illness that the person already has or could develop later in life.

The sources from which the Cas9 is produced do not violate the dignity of the human being in any of the stages of development. As a matter of fact, they do not abuse or misuse any other animal and natural resources. Creating Cas9 does not produce any byproducts that should be of concern for present and future generations. Embryos are not being harvested or frozen for this purpose.

The experiment of Junjiu Huang's team was with a defected human embryo, that according to them would have been discarded anyways.[63] This utilitarian approach to a human embryo, even if it carries an illness or defect, is definitely an area of concern for many ethicists and moral theologians. Scientists are divided among themselves when it comes to using human embryos. Most will agree that the moratorium on research with humans should be kept until confirming that genome editing is truly safe. Some scientists will be content once the level of safety is reached and they receive the green light for human experimentation; others are hesitant of tampering human genes and would rather stay focused on other animals and crops.[64] The use of embryos in any way, but especially research, is far from being resolved between ethicists and scientists.

There is no doubt that the cost involved with CRISPR/Cas9 is dramatically less than previous techniques. To the fact of being financially affordable and based on the

[63] See Parrington, *Redesigning Life*, 107.
[64] See ibid., 107.

experimentation done on other living creatures, scientist are trying to prove that there is also the benefit of no secondary effects to the recipient. That being the case, this could be a great healing method. It is not fully clear if the population in the developing countries and even those who are non-insured and underinsured in the developed countries could afford it. That remains to be seen until the FDA approves these techniques. Once this editing will be available, will it be a treatment for the financially privileged? If that is the case then the health conditions of those in a middle class and/or the wealthy class will enjoy better health conditions. On the contrary, the financially distressed members of society, who are already at a lower level of access to health and care, would become even more marginalized. This dynamic would foster an increased level of poverty for individuals and certain communities.

The *Universal Declaration of Bioethics and Human Rights* in its Article 12 calls for the due respect given to cultural diversity and pluralism. It is necessary to recognize the difference between culture and the persons themselves in that statement. Some people understand pluralism as a way to justify the need for socioeconomic diversity, and they interpret that it is an advantage for society to have distinct groups. In other words, according to such views society needs the gap between groups to keep the status quo: wealthy and poor, healthy and sick, strong and weak.

Virtues needed in clinical research

For decades one of the most common practices in clinical trials was to offer some patients / candidates the new medicine or treatment and to others a placebo. It was considered good scientific practice that the research team would not know which ones received the medicine and which ones did not. As time went by, the moral issue in question became the actual lack of treatment for those with the placebo. They were not being cared for. Even though there are

strong attempts to correct this practice, it still depends on the notion of the sacrifice of a few for the greater good.[65]

Another reality is that the people in the developing world are not focused on genetic illnesses. They have greater concerns like healing people with AIDS and malaria, or at least reduce these illnesses from spreading. In the list of diseases and treatments, genetic editing is on the agenda of those who are already enjoying better health and more sophisticated healthcare systems, those living in the developed world. They are the ones researching and investing resources; but also reaping the benefits.[66] Benefits for the people receiving the treatments and, like with the rest of the pharmaceutical industry and technology, for the private companies involved in any genetic enterprise.[67] They are for profit.

To address this issue Neil Messer, in his book *Respecting Life: Theology and Bioethics,* uses William May's virtue ethics[68] to argue in favor of applying some essential virtues to both clinical medicine and clinical research; virtues which could so easily seen as necessary in genetic editing. He highlights the virtue of ***benevolence***, that like all other virtues aims to promote the good of the person. Any attempt to modify genes should be done first and foremost for the good of the individual. This notion of the good of the individual can easily be distorted when 'good' is too subjective - an issue found in the developed countries since the end of the twentieth century. The overemphasis on the individuals' rights, desires and happiness has created a personalized concept of what is good. ***Prudence*** is needed in order to discern what it is really the best decision for the whole of the patient. ***Fidelity*** is recognizing that the interest of the

[65] See Neil G. Messer, *Respecting Life: Theology and Bioethics* (London: SCM Press, 2011), 150.
[66] See Lisa Sowle Cahill, *Theological Bioethics: Participation, Justice, and Change* (Washington, D.C.: Georgetown University Press, 2005), 217.
[67] See ibid., 216.
[68] See William F. May, "The Medical Covenant: An Ethics of Obligation or Virtue," in *Theological Analyses of the Clinical Encounter*, eds. Gerald P. McKenny and Jonathan R. Sande (Dordrecht: Kluwer Academic Press, 1994), 29-44.

patient goes before the benefits and interests of the doctor/therapist and in many ways also before the benefits of the rest of society. This aims at avoiding a utilitarian approach of the person. Messer reflects also on the virtue of ***public spiritedness***, which refers to collaborating with other fields and layers of society in order to achieve the desired good: relieve the person from illness and suffering.[69] Clearly, there is also a need for the virtue of ***truthfulness***, making sure that the researchers provide an honest report of their findings to the rest of the scientific world but also to that individual patient may become the subject of a trial.[70] As an overall umbrella for these virtues Messer insists that the theological virtue of ***charity*** is needed. By doing so it guarantees that the reason for pursuing research is not only for fame and money, but truly love for the neighbor.[71] The goal of practicing these virtues is to keep the research humane and dignified; this is quite a challenge when, for large transnational corporations, fame and money among others are also relevant factors.

It is important to reflect on how financial resources are allocated to genetic editing. At this point it is not possible to define carefully the costs for the patient or the health insurance because of the lack of approval by the FDA. In spite of this, it could be presumed that in theory some financial advantages may be attached to edit a mutation that is causing an illness. Depending on the illness, the amount of drugs needed, the treatments that are required and the care providers involved in order to treat and, hopefully, heal a person, could be very expensive both for the individual (or the family) and the health insurance (or taxpayers). If CRISPR/Cas9 could become an accurate and efficient technology, in theory it should be a one-time expense. Would this then be a more prudent and wise approach of using the research funds available?

[69] See Messer, *Respecting Life*, 154.
[70] See ibid., 156.
[71] See ibid., 163.

Moreover, most drug companies tend to focus on research to overcome widespread illnesses. There is a greater need and a higher demand to search for the best healing method; and at the same time this focus spreads the cost of the research investments, drug production and marketing. Hopefully this worldwide approach is a key motivator. However, the reality is that some diseases get more attention and resources than others, especially when treating people in the developed world. When there are fewer cases of a certain disease, the investment of human and financial resources changes. Usually research requires an extended length of time, therefore increasing its cost. Especially if the person sick is a child, the parents and most probably everyone who has met the child with this rare genetic illness would want to see some form of treatment and healing as soon as possible. Could genetic editing, especially with CRISPR/Cas9, provide the flexibility needed to address some of those rare conditions without having to engage in a decade of drug creation, trials and approvals?[72]

James Keenan, SJ, in his vast work in virtue ethics, recommends his own list of cardinal virtues. By considering how genetic diseases affect human dynamics, these virtues can be examined apart from the previous virtues. Keenan proposes ***justice*** (for the broad relations and interactions), ***fidelity*** (for particular relationship) and ***self-care*** (the preservation and care of the individual), to which he adds the virtue of ***prudence*** that brings harmony and balance between the other three.[73] Virtue ethics highlights the importance and the need of each person to become better, to be an improved version of themselves. It takes under consideration the persons' gifts and abilities, but also their limitations. For anyone involved in scientific research, the virtue of justice is essential, since it inspires the actions taking place in the laboratories and aims at

[72] See Reilly, *Orphan*, 334-335.
[73] See James Keenan, SJ, "What Does Virtue Ethics Bring to Genetics?" in *Genetics, Theology, Ethics: An Interdisciplinary Conversation, ed.* Lisa Sowle Cahill (New York: Crossroads/Herder, 2005), 102.

promoting equality. As Keenan says, "virtues aim for equality in the name of justice."[74] This equality is deeper than everyone getting the same amount or having the same opportunity, it inspires a greater respect for humanity. "Virtue ethicists therefore remind geneticists that their work is not a manipulation of some object-out-there but inevitably is a manipulation of our very selves."[75] Whatever is done in the research labs and with human trials is not only affecting my child, "because they are our progeny, we are affecting our human race."[76] The impact of healing somatic illnesses, germline editing (Chapter Two), and enhancements (Chapter Three) have on the human race, is why it is critical the involvement of everyone "in any dialogue on genetics because of their vested (self-) interest."[77]

The virtue of justice could be placed in tension with the other two virtues of fidelity and self-care, when the person desiring and approving genetic editing is deeply concerned for the well being and for the healing of their loved ones. As in many other health scenarios with ethical dilemmas, usually those pleading for the approval of the government, for the public to vote in favor of specific funding for research projects are people who have someone they love suffering or facing an illness. No outsider can question their love, not even when it is the same person pleading for herself as she longs for a 'normal' life. Love or fidelity is not what is being questioned here. What needs to be evaluated in this case is the actual practice of human genetic editing. The virtue of prudence can assist in placing the motivations, the methods and goods obtained on the balance, in order to compare the benefits for the entire humanity with the benefits for an individual.

[74] Keenan, "What Does Virtue Ethics," 100.
[75] Ibid., 107.
[76] Ibid., 107.
[77] Ibid., 107.

When research is not properly regulated by government agencies (acknowledging that these agencies are staffed with people who have their own limitations and biases), some entities sponsored by government and others operating completely with private funding, may take advantage of people in distress and with the desire to be healed or to have a loved one healed. As mentioned earlier, some researchers have already proceeded with clinical trials, even though there are still reservations with the methods and possible outcomes. Clearly it is a challenge to control these 'opportunities to be healed' in such an early stage of development, when they are being offered in a different country due to their more relaxed regulations.[78]

Teachings of the Magisterium

When approaching the possibility of clinical trials with embryos and fetus, two main concerns are: how to apply the previous rules of consent, and the difficulty of foreseeing the actual impact on the child to be born. The latter can only be confirmed after the birth, when nothing can be done to change it.[79] The overall approach with genetic editing, as with any other treatment and medication, is to determine the risk/benefit balance. When studying this balance, researchers, government agencies and society in general should always make sure that the benefits are greater than the risks.

The Congregation for the Doctrine of the Faith, in *Dignitas personae: On Certain Bioethical Questions*, speaking on behalf of the Church's Magisterium and in agreement to the previous arguments, provides the following statement:

> For a moral evaluation the following distinctions need to be kept in mind. Procedures used on somatic cells for strictly therapeutic purposes are in principle morally licit. Such actions seek to restore the normal genetic configuration of the patient or to counter damage caused by genetic anomalies or those related to other

[78] See National Academy, *Human Genome Editing*, 107.
[79] See ibid., 108.

> pathologies. Given that gene therapy can involve significant risks for the patient, the ethical principle must be observed according to which, in order to proceed to a therapeutic intervention, it is necessary to establish beforehand that the person being treated will not be exposed to risks to his health or physical integrity which are excessive or disproportionate to the gravity of the pathology for which a cure is sought. The informed consent of the patient or his legitimate representative is also required.[80]

The Congregation is **not** condemning or disapproving the possibilities of genetic editing. It reminds us that procedures on somatic cells meant to heal a person are morally licit. One key concern in *Dignitas personae* is that the consequences to the subject should not be "excessive or disproportionate" in comparison with the actual illness.

That being said about somatic illnesses, the next question is what about the genetic editing that is not limited to changing the body of the subject in the clinical trial, but also the future children and maybe grandchildren of this person? And that leads us to the next chapter.

[80] Congregation for the Doctrine of the Faith, *Dignitas personae*, no. 26.

Chapter

Genetic editing that impacts the germline cells

In the previous chapter, we indicated that CRISPR/Cas9 was used to modify and correct the mutations in the eye, the skin, the blood cells and the muscles. All of these mutations concern the somatic cells of the body. Another group of cells present in the body, but in a lesser quantity, are the germline cells. These cells are responsible for procreation, for the beginning of new life.

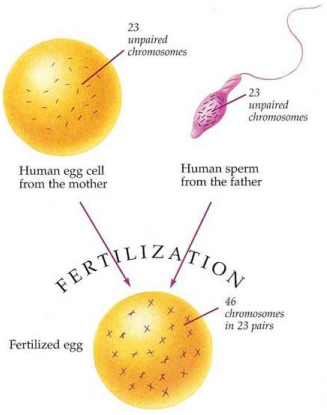

Figure 5. Germline cells.[81]

[81] Germline cells, last accessed October 28, 2019, http://glenda.mendoza.com.ph/2013/01/human-fertilization-development-and.html.

The actual procedure or technology for genetic editing would be the same for both the somatic and the germline cells. The main distinction between editing germline cells and somatic cells is that the potential benefits and the potential harms caused by modifying the gene could be inherited and passed down in the first case, but not in the second. Children and grandchildren will become bearers of the modification. Due to a lack of human trials and the limited experimentation and results with other animals, it has been impossible to determine the extent of these inherited benefits or harms.

One of the reasons that make this research appealing is that it could provide the parents an opportunity to have a healthy child that shares their genetic makeup. So far, if parents with a heritable genetic illness want to have a healthy child, their main and only guaranteed option of having one is to adopt a baby. In the more recent decades, parents have been relying on the services provided by sperm and egg banks. In this way they could find a healthy sperm or egg donor in order to circumvent the unhealthy parental inheritance. The dilemma is that in both cases, the adoption or the donor, the couple can say that neither child is 'fully our child'. As time goes by and more options are available to increase the opportunities of having a newborn with the parents' sperm and egg, the parents are more inclined to desire and explore them.

If all the illnesses that are caused by an inherited genetic mutation were combined, they would add up to maybe 5 to 7 % of the population. Therefore, each individual illness occurs at a lower percent. The incidence or the amount of patients with the illness becomes the key factor to determine the priority or the focus of the researchers. These lower numbers of cases impact the cost of the treatments and the research needed to promote healing, causing them to be more expensive per capita.[82]

[82] See National Academy, *Human Genome Editing*, 111.

One critical question that needs to be answered is: in real life and not just in theory, does the genetic edited material pass on to the descendants? Among the many experimental researches, one was done with rats. Some testicular stem cells were extracted from the rat, genetically edited with CRISPR/Cas9 and then transferred back to the rat's testicles. Before returning them, the stem cells left in the testicles were destroyed with chemotherapy. Once the rat mated, the offspring showed the genetic changes done by the researchers.[83] Therefore, based on this trial this type of gene editing does carry the modification down the line! Would the same thing happen with humans?

Some possibilities of mutations that could be addressed and have already appealed to scientists are BRCA1/BRCA2 and DMD. The BRCAs are genes related to the development of tumors in the breasts and the ovaries, causing cancer.[84] During the last decade, when women found out that they might have these mutated genes, one of the preventive measures was to remove the 'healthy' organ, even before experiencing any physical sign of the cancer. One of the most popular cases of this early approach to the illness, which received plenty of coverage by the media, was the case of the actress Angelina Jolie. In 2013 she had a mastectomy as a response to the results of her genetic testing, which showed positive and thus indicate the potential to develop breast cancer.[85] In cases like this one, could CRISPR/Cas9 provide the option of editing the gene carrying the mutation and thus avoid the elimination of the actual organ(s) and reducing the risk of developing the possible disease?

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[83] See Parrington, *Redesigning Life*, 179.
[84] See National Academy, *Human Genome Editing*, 114.
[85] "Angelina Jolie received widespread media attention in 2013 when she told the public that she'd tested positive for BRCA1, a gene associated with an increased risk of breast and ovarian cancers, and subsequently had a double mastectomy. Now research shows that this publicity did influence some women's intentions to seek out similar genetic testing." See "Study: The Angelina Jolie Effect on breast cancer screening," 2015, https://www.newswise.com/articles/study-the-angelina-jolie-effect-on-breast-cancer-screening.

If Duchenne muscular dystrophy (DMD)[86] were to be treated exclusively with somatic genetic editing, the most that could happen would be to reduce the symptoms of the illness considerably, but the person would not be healed completely since many tissues are being affected by this mutation. It seems that if DMD were to be treated using germline editing, the chances of eliminating the illness would be greater. As a side note, there could be as many as a third of the cases of DMD caused by new mutations that would not be recognized during the screening process.[87]

Our society is overwhelmed with loved ones who suffer from Alzheimer's disease. The risk of developing this illness is increased by mutations in the gene APOE4. In theory, if this gene could be modified, that would avoid or reduce the risk of Alzheimer. But in the microcosms of genetics, things are never simple and clear cut! Researchers have found that APOE4 appears to protect the liver from damages caused by hepatitis C. This raises a new dilemma. Would it be more advantageous for the body to keep this defense mechanism or to eliminate it?[88]

When and how to do the editing? One of the procedure options is to make the editing of the genes in the embryo. The problem could be that not all the cells become edited. Obviously, due to the size of the embryo and in order to avoid harming it, only a few cells should be removed for verification.[89] This is why clinicians would prefer to edit the gene within in vitro fertilization (IVF),[90] which brings us to the next section.

[86] See National Academy, *Human Genome Editing*, 115.
[87] See ibid., 116.
[88] See ibid., 118.
[89] See ibid., 116.
[90] See ibid., 117.

Experimentation

Before any of these procedures with CRISPR/Cas9 reaches clinical trials with humans, it has and is being tested on plants and animals. One possibility of genome editing that scientists would want is to observe if the germline modification works effectively through multiple generations, particularly in mosquitoes carrying the malaria parasite. If scientists could mutate the gene in the mosquito to make it resistant to the parasite instead of being a carrier, and if these mosquitoes continue to mate and procreate genetically modified mosquitoes, then they may have found a way to restrain the spreading of this illness. Research has shown that the modification is inherited by 99.5 of the offspring.[91] The concern at hand is what would be the environmental long term effect of having this vast number of genetically modified mosquitoes reproducing themselves.

Ethical issues with the secondary methods

Working with the gametes (egg or sperm) or the gametes precursors seems to guarantee that the actual mutation is being corrected before fertilization and then transferred into the uterus. These procedures take place outside the body and therefore they are called *in vitro fertilization* (IVF). It is necessary at this point to remind the reader that the teachings of the Catholic Church do not condone IVF, and there are plenty of documents discussing the morality behind it. (Since this research paper does not enter into the ethical discussion regarding IVF, if you want to learn more about the Catholic teachings available, a starting point would be the *Catechism of Catholic Church*.) To engage in that debate (which is important) would distract from focusing on genetic editing. For the sake of discussing genetic modification, it is necessary to recognize that IVF is presently practiced by many couples and it is used in many laboratories and in research.

[91] See Parrington, *Redesigning Life*, 174.

The Catholic Church applies the same teachings and expectations in regards to any work done with eggs and sperm to zygotes and embryos. The experimentations and procedures that take place at these stages of human development allow both scientists and families to pick and choose which embryos they want to keep and which ones they want to discard. Some embryos are discarded before implantation while others are discarded later in the development having, in most cases, to induce an abortion. In the case of either option, the termination of an embryo has generated a passionate ethical debate that is not part of this research. Although it is necessary to remember that all these debates are necessary, and that the Catholic Church upholds the sanctity of life from the moment of conception. Therefore, the official teaching on this matter is that all fertilized eggs, let it be in the womb or in a freezer, are human cells.

Hence, the official teaching of the Catholic Church has issues with the previous procedures and that unfortunately they are a common scientific practice. To these practices a new layer has been added: germline editing.

Ethical issues with germline editing

When posing the question of whether it is wise to proceed with germline genetic editing, there has to be an honest analysis of the balance between the benefits for the individual and the benefits for society. From the point of view of Catholic social teaching, it should be highlighted that the focus is an all inclusive society.

The most immediate benefit of germiline editing is personal: *my* child, *my* family, *my* descendants. Personal emotions carry a heavy weight in the decision-making process when a father or a mother believe they can free their future child and maybe grandchildren from a specific illness. To intensify the emotions of this scenario, an illness they might blame

themselves for being the carriers. From the legal point of view, in the United States, this general notion would fall under the 'rights' of the individuals: the right to procreate and the right for children to be healthy. In the situation where there is a high risk of illness, the possibility to have a healthy child that, with genetic corrections, can now survive the birth, the first few years of life and grow to be a healthy man or woman is very appealing to every parent.[92] In many debates, parents advocate for their 'right to have healthy children', while others may present as a problem the fact that the child is not consenting to genome editing. Even though parents are granted the right to choose what is best for their children and everyone believes that most parents would make the best decisions, the bottom line is that who is being impacted the most by this modification has no word and cannot express any consent whatsoever.[93]

In the United States, the government is neither expected to financially support nor to promote reproductive technologies.[94] In the *Consolidated Appropriation Act of 2016*, the U.S. Congress stated, "None of the funds available by this Act may be used … in research in which a human embryo is intentionally created or modified to include a heritable genetic modification."[95] That implies that this research is neither funded nor subsidized by the government, it is left to the private enterprises to invest their resources in it and therefore to provide the treatments when they will be available. This reality in itself will result in a higher price tag due to the market dynamic of competition, offer and demand, etc. If the government were to provide the financial support for the research, it would also be expected to disclose and share the information regarding the research. Data would be made public. Making the research public and sharing it

[92] See National Academy, *Human Genome Editing*, 120.
[93] See Kelly E. Ormond, Douglas P. Mortlock, Derek T. Scholes, Yvonne Bombard, Lawrence C. Brody, W. Andrew Faucett, Nanibaa' A. Garrison, Laura Hercher, Rosario Isasi, Anna Middleton, Kiran Musunuru, Daniel Shriner, Alice Virani, and Caroline E. Young, "Human Germline Genome Editing," *The American Journal of Human Genetics* 101, no. 2 (August 3, 2017), 171.
[94] See National Academy, *Human Genome Editing*, 121.
[95] US Congress, Consolidated Appropriations Act of 2016, HR 2029, 114 Congress, 1st session (January 5, 2015). https://www.congress.gov/bill/114th-congress/house-bill/2029/text.

with other research institutions does not necessarily happen in the private sector. Once the research is brought into the public arena, it allows for better oversight and a reduction of abuses.[96]

As mentioned in the previous chapter, one of the concerns with any form of genetic editing is the off-target changes. Since the research done with somatic illnesses is already ahead of those with inherited illnesses, the data provided can be very useful. There is a threshold or limit of how much off-target editing should be tolerated before it actually impacts the body causing new problems. In germline editing, because these new off-target mutations are also inherited and there is no knowledge available on how these mutations will be translated in future human generations, the level of tolerance should be lower than for somatic editing.[97] Even with other living species, it does take multiple generations to determine the impact of the off-target changes. The efficiency of scientific research comes from trial-and-error during the experimentation, and from collecting extensive data from all the trials. Clearly, any valuable data that would be available in the human trials of germline editing would take years and even decades before it could be recollected and studied. It would be necessary to observe the children and the grandchildren of those who underwent genetic editing. Realistically, to study cases for a minimum of twenty years does neither sound appealing nor practical for the research team nor the patients, especially in this era when everything seems to move so fast. Plus, there is the assumption that the person and their family would still want to be considered clinical subjects for scientific observation throughout those twenty or more years.

On the one hand, some scientists themselves argue in favor of not editing the genome when this can cause inherited results. Their approach is to let it be 'natural' and avoid to

[96] See Ormond et al., "Human Germline Genome Editing," 171.
[97] See National Academy, *Human Genome Editing*, 122.

intervene or impact the core of human life and design. On the other hand, others argue that the genome has already been altered by what is present in the environment such as contamination and radiation. These scientists believe that they would correct the mutations caused by a variety of these external factors, which in many cases were caused by humans themselves. These two different and opposite positions on the issue becomes more complicated when the reality is that "(t)here is no single human genome shared by all of humanity."[98] Therefore, creating a master plan or model to which everyone should match or abide is unrealistic. And if that were to happen, if a master model is set, then a few people would be determining for the rest of society what is normal and expected. As it could be anticipated, that would affect those who are considered to deviate from the base line.

As in the case of somatic editing, germline editing could have both positive and negative impacts for society. In the case of germline editing the most obvious advantage is that the child and the family that once were considered physically behind the rest of society due to their health would now be at an acceptable health level. If proven effective, this kind of treatment could reduce or even eradicate certain illnesses. By eliminating those illnesses, those who would have been ill if the editing would have not taken place, as well as their family members, will have a better opportunity to overcome the physical, financial and psychological burdens connected to that illness. This is all hypothetical, since there are other socio-economic factors that can be even more burdensome than a physical condition.

The main negative impact on the community and on society would be trying to create perfect healthy children. Our history has shown the ethical and social disasters that resulted from this approach.[99] For example, if a procedure like CRISPR/Cas9 was accessible only to a limited

[98] National Academy, *Human Genome Editing*, 124.
[99] See ibid., 123.

number of families and they were able to correct the mutations and therefore the diseases or conditions of their children, would those few families with access then become less tolerant to those in society who are struggling and will continue to struggle with the mutation and disease? There could be a regression in society's acceptance of children and adults with these conditions. Unfortunately, this could foster the mentality of 'better off if never born' which is a quick troubling response to many scenarios of illness. Those working for the rights and the dignity of people with disabilities tried so hard to eradicate this negative reaction and rejection. There are concrete signs of how this attitude towards 'imperfections' continues to be present in society. Just notice the considerable decline in the possible numbers of babies born with Down syndrome. Many parents choose non-existence over existence when they find out about their child's genetic condition.[100]

Human dignity

Within Christian teaching there is a long tradition to define, recognize and uphold human dignity. Throughout the centuries it has developed to the point of recognizing that every person – without distinction of race, gender, religion, education, religion or financial status – deserves respect and care by the simple fact of being a human being. The Church tradition teaches that everyone has been created in the image and likeness of God. The twentieth century brought that truth to new levels, and one of them concerns people with disabilities. Now more than ever before, anyone struggling with any form of disability is encouraged and supported in order to integrate themselves as much as possible into society. Among many things, special programs for education and training, as well as new equipments and technologies have been developed to assist people with disabilities to be part of everyday school, work and church life. A sign of

[100] See Ormond et al., "Human Germline Genome Editing," 171.

these changes is that for centuries we built churches to be as high as possible to represent the nearness to heaven, now many of new churches are built without a single step to enter, and to the older buildings they are adding ramps and elevators. At the same time, all the members of these communities are frequently reminded and challenged not to look down, not to reject those who are struggling physically or mentally. If, on the one hand, genome editing is another tool that could help overcome a disability, on the other hand, some advocates for people with disabilities believe that this could be a step back. They believe that once again they will and are already seen as imperfect and therefore they need to be 'corrected'.[101] Is there a real danger of reversing the progress made and returning to see people with disabilities as a mistake or a burden? When we read and hear the arguments used in favor of genetic editing, the implication is that 'people with these conditions need to be fixed'. Without doubt, there is a desire to provide healing for those who are ill. For centuries people have been searching for remedies and resources to facilitate healing. The sad reality is when persons are defined by their illness. How often society addressed a person as leper, "mongoloid" or "retarded"? There are serious concerns that one of the results of reducing disabilities in society "will necessary decrease empathy, acceptance, or integration of those who have them."[102] This does not mean that nothing should be done to improve the health and the quality of life of a person with a disability. It is more an issue of approach and mindset of the rest of society and the people involved in the research and treatment. The language used with and in reference to the subject, and viewing the subject as a person and not an experiment, set the tone on how the illness and people are seen.

The concept of human dignity needs to be cherished throughout the entire process: research and clinical trials with gametes, embryos, children or adults. Frequently, our society,

[101] See Robert Song, *Human Genetics: Fabricating the Future* (Cleveland, OH: The Pilgrim Press, 2002), 56-58.
[102] National Academy, *Human Genome Editing*, 127.

including scientists, needs to be reminded that every person has dignity at every stage of their life. Many societies improved in their acceptance of every living human being. Where society still needs to be challenged is in allocating that dignity to every stage of humanity and not just to full living beings. There is a need to express dignity even in caring for the dead. Because they were humans, their bodies deserve due care and respect. They should not just be dumped or abandoned until they decompose. The rich variety of funeral rites shows that these dead bodies still carry the dignity that is owed to them.

On the other side of the spectrum of life, it is also important to accept and promote the dignity of 'future humans', those who are not born yet but clearly will be persons with a rightly deserved dignity.[103] In other words, we should advocate for the dignity of the fetus and the embryo. Besides these three long standing stages of being human–past, present and future– the Rev. Dr. Jan C. Heller refers to the "problem of contingent future persons".[104] He highlights the lack of consent and freedom in the case of the newly created embryo. A human life is now determined by the timing of the fertilization in the lab, the choosing of the desired egg, sperm and embryo, and genetically modifying them. All these steps and decisions are being made by a mother and a father, and now also by a third party, which is not the child. Even though there is love between the couple, the actual existence of this new life is not the result of a loving sexual act between the couple. It depends on the work of scientist in a lab. Procreation moved from a random manifestation of nature to the mechanical decisions and actions of a group of outsiders. Therefore, will these future human lives lose or be deprived of some of their human dignity because now depend on the work of some scientists in a lab? Could this child be seen as the

[103] See Jan C. Heller, "Using Human Dignity to Constrain Genetic Research and Development: When It Works and When It Does Not," in *Genetics and Ethics: An Interdisciplinary Study*, ed. Gerard Magill (St. Louis: Saint Louis University Press, 2004), 117.
[104] Ibid., 118.

property of a corporation? An experience similar to this possible scenario that is already available for observation is the children being born by IVF. These parents love their children. There is no doubt that these children are theirs. The child is formed by the egg and sperm of mom and dad, maybe with pre-selection but without tampering the genetic makeup. The difference in this new probable scenario would be that the genes are being modified. Could this modification have an impact on the relationship between parents and child?

Social justice

An already existing ethical debate in dealing with and treating rare diseases is the amount of human and financial resources invested in this kind of research and clinical trials and whether these resources could be allocated to benefit and heal millions of people with diseases when there are already accessible treatments. The limit of this statement is that, if for example the United States would stop or reduce the resources invested to study 'rare' illnesses, those resources would not necessarily be directed and used to attend global health issues.[105] Without doubt, to find a cure for those rare genetic diseases is a sizable investment. If the need to find a balance and a proportion between investing resources and the number of beneficiaries has a social justice overtone, without hesitation it is also a matter of social justice to find ways of healing someone even when they are among the unfortunate few suffering from health issues.

By studying the history of humanity, there are several heartbreaking events that provide scenarios and obvious reasons to be concerned with the unknown long-term effects of germline editing. It is possible that these modifications could create a sense of biological superiority and even supremacy. They would impact everyday human interactions.[106] There is even the concern

[105] See National Academy, *Human Genome Editing*, 128.
[106] See ibid., 128.

that what started as a healing mechanism could be distorted through time and be used in other less honorable, dignified and just ways. As far as it can be predicted, if these modifications could actually take place, the result would not be a homogenous society, but most probably a subgroup within a society. Once a subgroup is allowed to overcome a mutation in their germline, it leaves the 'rest' of society with the undesirable potential trait, fostering then a new level of prejudice. "Genetic disease, once a universal common denominator, could instead become an artifact of class, geographic location, and culture."[107]

The National Academies of Science, Engineering and Medicine acknowledge an openness to research with heritable genome editing as long as certain key criteria are fulfilled[108] and foster justice. The argument is that there is no other alternative available and this method of genetic editing is the only way to prevent a specific illness. The final product of the modification should match what is considered the normal standards in society and with very few or no off-targets that can cause negative effects. The data regarding the risks and benefits should be as accurate as possible. There has to be a follow up of the patient but also of his or her descendants. In time, it will be necessary to assess the impact on society, and where this person fits within the society. Finally, the most common approach to all research is to guarantee that there is no abuse or misuse of the technology.

Ormond et al. stress that, "Future clinical application of human germline genome editing should not proceed unless, at a minimum, there is (a) a compelling medical rationale, (b) an evidence base that supports its clinical use, (c) an ethical justification, and (d) a transparent public process to solicit and incorporate stakeholder input."[109]

[107] Ormond et al., "Human Germline Genome Editing," 172.
[108] See National Academy, *Human Genome Editing*, 134-135.
[109] Ormond et al., "Human Germline Genome Editing," 173.

Going back in time, the *Convention on Human Rights and Biomedicine* of the Council of Europe in 1997 and the 1997 UNESCO's *Universal Declaration on the Human Genome and Human Rights* requested that any tampering of the human genome should not be carried on by the descendants of the person. This is a clear position that aims to avoid germline editing.[110]

Solidarity

When the Catholic Church uses the term solidarity, she refers to that deep relationship between people, through which they share the joys but especially the struggles with a sincere empathy. This care and compassion for the other move the heart to respond with the desire to foster, protect, and promote the well being of the other in every possible way. That sense of solidarity serves as a driving force to care for people who are sharing the same socio-economic level, for those who are rich to look out for those who are poor and, among those who are sick and the healthy, to care for the ill. Solidarity is the virtue that guarantees a just distribution of resources, not only because it is the right thing to do, but because 'you are my brother, you are my sister and I care for your well being'.

In the case of germline editing, solidarity implies that all those involved–the scientists, those providing genetic material, the families of those who are sick or could be, the general public, the private businesses, the government and many others–are concerned about all the possible impacts of genetically editing a sperm or an egg, and the children that will be born from these modifications. This sincere concern and protection cannot be limited to the present time.

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[110] See David A. Jones, "Germ-line Genetic Engineering: a Critical Look at Magisterial Catholic Teaching," *Christian Bioethics* 18, no. 2 (2012): 127-128. For more information on these documents:
UNESCO, Universal Declaration on the Human Genome and Human Rights, 1997, http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html.
Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine,* 1997, https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98.

Providing what is best must go beyond the children already born. There should also be an awareness of those yet to come, the future generations. A beautiful example of this solidarity beyond the present generation is all the hype about global changes in climate and contamination, and the commitment to guarantee a healthy planet for our grandchildren and their grandchildren.

A simple way to be in solidarity with the communities of the developing world is to make sure that those who actually contributed to the research by being themselves part of the trials or providing resources, may reap from the benefits. It is unfortunate when a country, a village or an individual that was actively involved in the experimentation stages of a medication or treatment, never get to benefit from what was achieved. At the same time, all the participants involved in genetic editing need to recognize that if they are going to partake of the benefits they also have to share the burdens.

A sense of solidarity should be present in the debate about patents. In the last few decades, there has been plenty of genetic research and discoveries. For the most part, what scientists have done is 'discover' something that was already there, not necessarily creating something new. The human genetic map is not a creation of an individual or a team; it is part of nature and it carries the genetic information regarding how the human body is made and functions. With gene editing, what scientists did was to help uncover this information. A patent is meant to protect an invention and not a discovery in nature; but there has been patent applications "filed for genes and segments of genes."[111] When dealing with how to use CRISPR/Cas 9 there is further debate: the editing mechanism can be found naturally in bacteria, but it is also true that it had to be modified in order to make the right DNA edits.[112] Therefore, is

[111] Cahill, *Theological Bioethics*, 220.
[112] See John J. Mulvihill, Benjamin Capps, Yann Joly, Tamra Lysaght, Hub A. E. Zwart, and Ruth Chadwick, The International Human Genome Organisation (HUGO) Committee of Ethics, Law, and Society (CELS), "Ethical

it technologically produced (invented) or natural? The concern of turning it into a human creation is that it will involve patenting the CRISPR/Cas9.[113] Patenting would imply having to pay for the license to use it, which would increase the cost of the procedure and enrich a few stakeholders. Or patenting could be kept under the control of a few corporations. The ideal would be for the scientists to see CRISPR/Cas9 as part of nature and take advantage of this opportunity to be in solidarity with other researchers by sharing their success stories, and in solidarity with those who are ill – maybe one day eradicating their illness.[114]

Last but not least, there has to be a level of solidarity towards the earth, the world in which we live. Human beings have the responsibility to be good stewards of creation and protect it from being harmed. When studying an array of mutations in the human body, many of them are caused by the environment. Unfortunately, some of the environmental factors causing mutations, like chemicals and radiation, were created by humans. These mutations are the consequences of humans exposing other humans to these risks. With or without awareness, people are impacting the environment in negative ways and as a result of these actions they are at the same time causing negative effects on their own species and on the ecosystem. (Maybe those creatures from the movie *Rampage* could become real after all!)

Teaching of the Magisterium

The Catholic Magisterium has been slow in responding to gene editing, a technology that is developing very fast. The main sources of teachings available are basically limited to *Donum*

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issues of CRISPR technology and gene editing through the lens of solidarity," *British Medical Bulletin* 122, no. 1 (2017): 22.

[113] The attempts to obtain a patent for CRISPR/Cas9 began in 2012 and the battle is ongoing between those who claim the right for this patent. Also, should a patent be granted to anyone? For developing stories on this debate until September 2019, see http://www.mondaq.com/unitedstates/x/847330/Patent/Another+Round+In+The+US+CRISPR+Patent+Dispute.

[114] See Mulvihill et al., "Ethical issues of CRISPR technology," 24.

Vitae (1987) and *Dignitas personae: on Certain Bioethical Questions* (2008).[115] As it can be imagined, due to the later developments of these scientific discoveries, Scripture and Tradition lack direct insights in this area. The early Church Fathers had no notion about genetics, and therefore could not incorporate them in their teachings. But they experienced illness and cared for the sick.

One enlightening approach comes from St. Basil the Great. In *The Long Rules* he writes about the art of medicine. He explains: "In as much as our body is susceptible to various hurts, some attacking from without and some from within by reason of the food we eat, and since the body suffers affliction from both excess and efficiency, the medical art has been vouchsafed us by God, who directs our whole life, as a model for the cure of the soul, to guide us in the removal of what is superfluous and in the addition of what is lacking."[116] For Basil, it is important to help his readers understand that this "medical art was given to us to relieve the sick, in some degree at least."[117] God blessed humans with this art, but God is also providing the resources available in the world to be used for the healing. "(T)he obtaining of that natural virtue which is in the roots and flowers, leaves, fruits, and juices, or in such metals or products of the sea as are found especially suitable for bodily health, is to be viewed in the same way as the procuring of food and drink."[118] But Basil recognizes that there has to be a limit to the amount of effort and to what is being sacrificed. "Whatever requires an undue amount of thought or trouble or involves

[115] See Congregation for the Doctrine of the Faith, *Dignitas personae: On Certain Bioethical Questions,* 2008. Congregation for the Doctrine of the Faith, *Donum Vitae,* 1987.
[116] Basil the Great, "Question 55," in "The Long Rules," *St. Basil: Ascetical Works*, trans. M. Monica Wagner, *The Fathers of the Church: A New Translation*, Vol. 9 (Washington, D.C.: Catholic University of America Press, 1962), 330-331.
[117] Ibid., 331.
[118] Ibid., 332.

a large expenditure of effort and causes our whole life to revolve, as it were, around solicitude for the flesh must be avoided by Christians."[119]

Maybe Basil's most important contribution to his support of medicine concerns its purpose: "Consequently, we must take great care to employ this medical art, if it should be necessary, not as making it wholly accountable for our state of health or illness, but as redounding to the glory of God and as a parallel to the care given the soul."[120] Basil concludes that whatever medical treatment is being done, it should be first and foremost for the spiritual well-being of the person, to bring people closer to God. Treatment should be a path to God and a recognition that, when it works, the ultimate praise should be for the Lord, in order to avoid making medicine an idol.[121]

Saint Basil also foreworns the reader about using the art of medicine in the wrong way, with a different and even harmful purpose for which God intended it to be used.[122] At the same time, there is a long Christian tradition concerning suffering, which clearly has roots in the Old Testament, for example in the book of Job. The spiritual challenge could also be accepting the disease with patience and as an opportunity to develop patience.[123]

What did Saint Thomas Aquinas contribute to this topic, when he himself lacked knowledge about this genetic world? In the *Summa Theologiae* (Ia, q.75 and q. 76), he wrote about the human soul, which gives substantial form to each person. This means that it is what makes the human being a human, different from other animated creatures, but similar and connected to all other humans. The soul allows people to understand who they are and what is everything else around them, something that, for Aquinas, a dog or any other animal cannot do.

[119] Basil the Great, "Question 55," 332.
[120] Ibid., 332.
[121] See ibid., 334.
[122] See ibid., 333.
[123] See ibid., 335.

Aquinas places the persons apart from plants and birds, but also acknowledges that they are neither angels nor God. In simple words, the understanding and the will that humans possess place them in a different category. They are not spiritual (non material) beings, but they are not solely material. These previous concepts and teachings can be extrapolated and adapted to apply them to the present ethical questions raised by genetics. For example, one of the practical conclusions that can be reached from Aquinas' earlier arguments is that the human body should not be treated as all other minerals, vegetation or animals on the planet, since it is not just one more thing.

At the present time the main sources of Catholic teaching in regards to genetic editing can be found in *Donum Vitae*, *Dignitas personae* and the *Catechism of the Catholic Church* (no. 2275, which quotes the previous two documents).[124] When we read the arguments posed against genetic editing, and as a matter of fact against anything related to the human genes, the concerns at hand are mainly with IVF, the lack of sexual union to create life, and eugenics. Since procedures of genetic editing are not yet fully developed, and therefore are not yet approved for human trials, one wonders what the theological reaction would be if gene editing was approved for trials. Hypothetically, if genetic editing for an illness takes place within the sperm cells, causing modifications before cell differentiation, the egg is fertilized by the sperm when the couple has intercourse, and the development of the embryo is completely natural, without any outside intervention, would this scenario then be accepted by the Church's Magisterium?[125] Clearly, IVF would not be needed and intercourse would occur without separation of the unity

[124] See Congregation for the Doctrine of the Faith, *Dignitas personae: On Certain Bioethical Questions,* 2008. Congregation for the Doctrine of the Faith, *Donum Vitae,* 1987. *Catechism of the Catholic Church,* 2nd ed., Washington, D.C.: United States Catholic Conference, 2000.
[125] See Jones, "Germ-line Genetic Engineering," 130-131.

and procreative dimensions, therefore they would be no-issues with the 'new' procedure; what remains is the question of eugenics.

Donum Vitae (no. I.6) states the following:

> *Certain attempts to influence chromosomic or genetic inheritance are not therapeutic but are aimed at producing human beings selected according to sex or other predetermined qualities. These manipulations are contrary to the personal dignity of the human being and his or her integrity and identity.* Therefore in no way can they be justified on the grounds of possible beneficial consequences for future humanity.

This statement refers to selecting the gender of the child or "other predetermined qualities". The term 'qualities' addressed at the beginning of the sentence refers to non therapeutic conditions. This could be parents looking to select the color of the eyes or another physical quality of their future child. It seems that the main concern behind this statement is to avoid eugenics, which is a legitimate concern and will be addressed in the next chapter. Could this statement indicate openness and acceptance to a certain type of editing that would be carried on genetically by the offspring, if what is being modified is an illness (therapeutic) in contrast to choosing characteristics (non therapeutic)?

Twenty years after *Donum Vitae*, the Magisterium provided new insights with *Dignitas personae.* In no. 26 the Declaration makes the following statement:

> *Procedures used on somatic cells for strictly therapeutic purposes are in principle morally licit.* Such actions seek to restore the normal genetic configuration of the patient or to counter damage caused by genetic anomalies or those related to other pathologies. … The moral evaluation of *germ line cell therapy* is different. Whatever genetic modifications are effected on the germ cells of a person will be transmitted to any potential offspring. Because the risks connected to any genetic manipulation are considerable and as yet not fully controllable, *in the present state of research, it is not morally permissible to act in a way that may cause possible harm to the resulting progeny.* In the hypothesis of gene therapy on the embryo, it needs to be added that this only takes place in the context of *in vitro* fertilization and thus runs up against all the ethical objections to such procedures. For these reasons, therefore, it must be stated that, in its current state, germ line cell therapy in all its forms is morally illicit.

On the one hand, this document supports somatic genetic editing, as long as it is therapeutic. The procedures are restoring the human body to the ideal healthy level. On the other hand, modifying the germline is illicit because of the "risks connected", "yet not fully controllable", and "in the context of *in vitro* fertilization". The first two arguments acknowledge that there are still unknown data and information. As a general position towards human dignity, the body and the person should not be used randomly and carelessly for experimentation; definitely, 'let us try this out and see what happens' would not be condoned. In spite of the teachings of the Church, however, researchers will continue to experiment until it is safe to have human trials. Once these trials will show that the healing of the illness is carried out genetically without negative consequences to the offspring, scientists would address the conditions and concerns stated in *Dignitas personae.* Would that be enough to sway the position from being morally illicit to licit?

Scripture

It is impossible to articulate a Christian theological discussion without relying on the Bible. When looking for arguments within the Scriptures, the best texts that can be used to argue in favor and against germline editing come from the book of Genesis. Those in favor of all or any aspect of genetic editing might read Genesis chapters 1-2.[126] The supportive points are that everything that God created is good, and that God created human beings "in our image, after our likeness" (Gen 1:26). "God created man in his image; in the divine image he created him; male and female he created them" (Gen 1:27). That being the case, then humans are also co-creators

[126] The scripture quotes are taken from: *The New American Bible* (Wichita, KS: Saint Jerome Press, 1991).

with God and are called to actively continue the evolution, the progression, the growth and the improvement of creation. The *Catechism of the Catholic Church* states in no. 307:

> God thus enables men to be intelligent and free causes in order to complete the work of creation, to perfect its harmony for their own good and that of their neighbors. Though often unconscious collaborators with God's will, they can also enter deliberately into the divine plan by their actions, their prayers and their sufferings. They then fully become "God's fellow workers" and co-workers for his kingdom.

This allows some people to conclude that this responsibility includes improving the human body. But if it is true that humans have this responsibility, they also have the duty to do so "in line with the divine intention."[127]

The second story of creation uses the images of clay and breath: "the Lord God formed the man out of the clay of the ground and blew into his nostrils the breath of life, and so man became a living being" (Gen 2:7). This 'clay', this raw material, can be seen as that 'common ground' between all human beings and that which connects all of them with each other. Some theologians see genetic material as sacred; hence, it should not be changed.[128] Others would argue that the respect owed to the human body does not exclude introducing changes because the body, and therefore the person, has already experienced many changes throughout one's life.[129] There are so many things that impact the body physically and therefore psychologically: education, environment, surgeries, etc. All these external agents change the person and sometimes they have a profound impact on individuals and communities, but they do not reduce or eliminate human dignity and identity. Due to arguments like these, some theologians can see the possibility of accepting genome editing, even in the case of germline cells.[130]

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[127] Cahill, *Theological Bioethics*, 224.
[128] See Koios, "Theological Anthropology and Human Germ-Line Intervention," 190.
[129] See ibid., 192.
[130] See ibid., 192.

If, at any point, human trials will be permitted, there are at least two biblical perspectives or criteria that could be upheld. Genesis 1:27 recalls the creation of humans in the image of God and therefore made free. Therefore, the first expectation is that the children to be born should "be moral agents, that is, to be free."[131] Whatever is changed in the person should not affect that freedom. Then, in Genesis 1:28, God commanded to "be fertile and multiply." Therefore, after genetic editing, the persons to be born "must retain their nature as men and women, and their ability to procreate as man and woman."[132]

To support their arguments some theologians who are against tampering the genes might rely on the same verses of Genesis chapters 1 and 2, with the difference that they could highlight that humans are still mere creatures and that by modifying the human body they are 'playing God'. This 'playing God' is a common phrase mostly used by secular and theological authors whenever there has been a direct intervention with the creation of life, e.g., IVF, cloning or genetic editing. Another biblical support against tampering the germline may be found in Genesis 3:5. Immediately after both accounts of Creation, the story presents the temptation: "you will be like gods who know what is good and what is bad" and the Fall that is caused by human pride.[133] Clearly, there has been plenty of proof that when humans want to become God or be as powerful as a god, and the results were quite negative and destructive. In order to conquer or balance pride, there needs to be an active practice and cultivation of humility.

The virtue of humility

In the *City of God* (XIV, 13) St. Augustine wrote about humility as a response to the pride of the Fall:

[131] Koios, "Theological Anthropology," 191.
[132] Ibid., 191.
[133] See Jones, "Germ-line Genetic Engineering," 135.

> There is, therefore, something in humility which, strangely enough, exalts the heart, and something in pride which debases it. This seems, indeed, to be contradictory, that loftiness should debase and lowliness exalt. But pious humility enables us to submit to what is above us; and nothing is more exalted and above us than God; and therefore humility, by making us subject to God, exalts us.[134]

Therefore, it is valuable is to foster the virtue of humility in the hearts of scientists and parents. So that in developing genetic editing and in procreation itself, it is critical to put aside any unhealthy pride, which convinces the mind that we can make a better human being than the one made by God. Humility acknowledges and accepts God's ongoing intervention in creation. Humility allows us to receive and appreciate every child as a gift, a child with or without a defect or illness, a child in which God "blew into his nostrils the breath of life" (Gen 2:7).

[134] Augustine, *City of God,* last accessed 11/4/2019, www.newadvent.org/fathers/120114.htm.

Chapter

Genetic editing to enhance some elements in the genetic makeup of the child

Understanding enhancement and perfection

Aiming for perfection is neither a new concept in the secular nor Christian traditions. In his Sermon on the Mount Jesus himself taught his disciples to aspire for perfection: "Be perfect as our heavenly Father is perfect" (Matt 5:48). Since then to the present time, the challenge is to understand what is implied by the term 'perfection'. Based on biblical exegesis, theological developments and spirituality, perfection refers to completion, the person reaching the fullness of her capacity.[135] What are those qualities, gifts and talents that persons should improve or perfect within themselves? Since God created each person with particular and distinct characteristics, each person should not only work on improving these, but must also do it so that one's whole life reaches its fullness. And this perfection can only be reached with God's help. As Christians, we

[135] See James F. Keenan, "Perfecting Ourselves: On Christian Tradition and Enhancement," *Southern Medical Journal* 100, no. 1 (January 2007): 96.

believe that the absolute fullness of perfection will only be achieved once the person reunites with God in heaven, since "heaven is the ultimate end and fulfillment of the deepest human longings, the state of supreme, definitive happiness."[136]

In the *Summa Theologiae* (I, q.4) Thomas Aquinas explains how all perfection in the world is achieved through God, since God is the source and the cause of perfection. God's perfection implies that there is no need or space for improvement. It is already reached. Since human existence is dependent on God, human beings share in the perfection of the one who created them. "All created things, so far as they are beings, are like God as the first and universal principle of all being"[137] (I, q.4 art. 3). Therefore, existence and perfection are gifts from God, which the human being receives and enjoys, often without acknowledging the source.

A difficulty with this understanding of perfection is that it has a strong Christian foundation, and therefore, not everyone will agree with it. Civil society relies on other versions of perfection, sometimes focusing on external appearance or financial gain.[138] Obviously, these perfections are based on standards created or defined by the society of the time; therefore, these standards will change throughout the years. At the same time, caution must be taken that perfection is not distorted into a false sense of personal dislike.[139] Instead of improving the self, people might desire to change their being to become some 'other perfect' being. Many times that desired perfection is someone else's lifestyle, appearance, family life or possessions. As described earlier, perfection is bringing the potential of who we are to its fullness. And since each person is made different, the 'final perfect product' must also be different. The challenge is to believe and accept that if perfection brings us closer to God, who is the source of all attributes,

[136] *Catechism of the Catholic Church*, no. 1024.
[137] Thomas Aquinas, *Summa of the Summa,* ed. Peter Kreeft (San Francisco: Ignatius Press, 1990).
[138] See Keenan, "Perfecting Ourselves," 97.
[139] See ibid., 96.

then God is the one setting the goal. When God's call, vision, and gifts are not recognized and considered as part of the person's ultimate goal, one of the dangers is to turn the personal experience in what is normative.[140] Unfortunately, some people have underestimated their own capacity and level of perfection, which may cause on certain occasions to be off-track or short from being as perfect as they could be in this life.

Today the term perfection is also translated or equated to the concept of enhancement. The *Merriam-Webster Dictionary* defines 'enhance' as "to increase or improve in value, quality, desirability, or attractiveness."[141] It is interesting to note that to enhance is commonly applied to objects: people work hard to enhance cars, houses, and technology. Within certain social circles, now the term is frequently used, accepted, and promoted for human beings. This approach may be observed when, through utilitarian and materialistic lenses, the human body and the person may be seen as one more product or thing to be improved, enhanced and, therefore, perfected.

Since every person is called by God to be perfect, this desire for perfection moves them to go beyond the self, towards other people and things around them. Within the richness of cultures and countries, all human beings share similar relational dynamics towards themselves and the rest of humanity. Humans naturally care and protect their own selves. The need to be nourished, healthy, sheltered and safe from any harm are some examples of basic common motivations across the borders of space and time. Moreover, human beings do not live in isolation. They are born and raised within a family and a community which fostered that sense of responsibility for the well-being of their neighbor. Then, when humans are concerned about having perfect conditions for themselves and their community, they become more aware and

[140] See Keenan, "Perfecting Ourselves," 97.
[141] https://www.merriam-webster.com/dictionary.

better stewards of the whole creation. It is this natural human reality that calls for solidarity towards oneself, the neighbor, and the entire world.[142]

In the previous chapters, genetic editing with CRISPR/Cas9 was considered as a possibility to heal or to prevent an illness. Without any doubt that would be a dream turned into reality for many parents and grandparents who also suffer due to the struggles of their little ones. This dream would be to free people from illness, pain, premature death, and some would even say, to provide for them a 'normal' life. In the present time, depending on the illness or condition, it remains only a dream or hope.

Enhancement, however, is quite different. The dream or proposal is not to help a person or family to overcome an illness, but to find ways to improve certain qualities of the child. The intentions are not to heal, but as it is commonly said, 'to enhance.'

At the same time, we need to remember that the technology for enhancement with genetic editing would be also using CRISPR. And it could be applied on both: somatic cells or germline.

The role of eugenics

Throughout the history of humanity one of the common struggles, which every culture had to face and to address, was how to deal with the sick and disabled members of the society, those members of the community that could be contagious, could not be self-sufficient and independent, or could be considered a 'burden' to their family and society. We can try to imagine several centuries ago how difficult it must have been to diagnose and treat certain illnesses, especially in the case of communities or families with limited resources, knowledge, and medical technology. During the nineteenth and twentieth centuries, humanity found new

[142] See Keenan, "What Does Virtue Ethics Bring to Genetics?," 101.

ways of addressing illnesses and treatments. Since then, scientists have been discovering and gathering more information about hereditary illnesses and conditions, about genes and chromosomes even at the point of providing new solutions to diagnose and treat some of them.

In an ethically problematic way, the 'science of eugenics' was formally introduced to improve the qualities of a race or a community by encouraging the human mating of certain individuals but prohibiting it for others. Therefore, in the *Merriam-Webster Dictionary*, the word *eugenics* is defined as: "a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed."[143] This scientific and social approach impacted society in such a way that those who had the genetic traits that were considered socially undesirable were in some cases sterilized.[144] Quite often the people sterilized were living in mental institutions or were immigrants. Some ethnic groups, which were considered as inferior by dominant white Caucasians, experienced rejection from those with political and/or financial power, even to the level of becoming victims of genocide. As deplorable as these actions seem to us now, what happened in Nazi Germany, is still lingering or creeping into different societies with similar premises (a sense of superiority) or desires (purify or improve the race). This unacceptable racist mentality can be observed even in some of the television news broadcasting, when those interviewed make comments or are holding signs with degrading contents about certain groups of peoples.

As a result of such a horrendous use of science, many countries and the United Nations created laws, policies and inspection teams, which try to respond as soon as possible when the leaders of a nation or certain groups give signs of targeting another ethnic or religious group. Unfortunately, these defenders have neither been quick responders at all times, nor effective in

[143] https://www.merriam-webster.com/dictionary.
[144] See Song, *Human Genetics*, 42.

stopping those who believe in and practice eugenics and racial discrimination. The sad reality is that sometimes these experimental practices can be taking place out of the sight of inspectors and enforcers of human rights. Therefore, targeted individuals and groups can still be the source of racial and eugenic experimentation aiming at extinction or at least control of their growth within the community.

The eugenic mindset tries to give the impression of pursuing almost an altruistic cause. For example, eugenics claims that it wants to improve the human race by increasing the levels of intelligence of chosen individuals. Moreover, eugenics claims that it can influence and even accelerate human evolution, which could take thousands of millions of years without any intervention.[145] Too slow for some people! Basically, the eugenic goal is to accelerate biological evolution by enhancing the genetic characteristics of a child or of a whole group within the society. What eugenics seems to forget is that *nature* has its own course and time frame. At this point in time, it would be impossible to predict what would be the natural result of human development if allowed to run its natural process for centuries. It is impossible to predict and replace natural selection.[146] The desired outcome of genetic editing might sound like and could actually be considered by some a noble one; but what needs to be observed and evaluated is the mentality of those who promote genetic enhancement *now* by comparing it with those who have tried to achieve these improvements in the past.

With the DNA discoveries in the 1950s and 1960s, a new level of eugenics began.[147] The goal was not to match the 'right people' together in order for them to give birth to healthier children or to discourage or make sure that the 'undesirables' would not procreate. New scientific methods were developed attempting to avoid or reduce the number of people born with

[145] See National Academy, *Human Genome Editing*, 154.
[146] See Song, *Human Genetics*, 41.
[147] See National Academy, *Human Genome Editing,* 155.

unwanted conditions. In the practice of eugenics in the 1920s and 1930s, to control healthy genetic combinations, no external or third party intervention in the actual process of procreation was possible. People were born after the traditional intercourse between a man and a woman. In the latter part of the twentieth century, with reproductive technologies, a new era began and it became possible to choose the egg or sperm, or embryo.

Imperfections and sufferings

Social pressure is a relevant factor in ethical decision-making. Family members, friends and public media are often pushing couples to have not just a healthy child but a 'perfect' child. When science is able to reduce or eliminate the possible genetic illnesses of a child, it "solves two problems at once: it relieves suffering, and it is less costly in terms of personal commitment and economic outlay."[148] The high cost of living in developed countries, including healthcare, might discourage families and communities to accept open-handed a person affected by a long term illness or condition. In some developing countries with higher levels of poverty, a variety of programs and incentives have been promoted to discourage having children in general.

Suffering deserves its own attention. In Western civilization, increasingly there seems to be a greater difficulty handling the experience of suffering. There is an increased aversion to face the physical pain in one's own body and, at the same time, the personal sacrifice necessary in caring for someone else who is ill or suffers from a disability. All forms of suffering seem futile, and therefore, there is an inability to deal with my own or another's physical struggles in a constructive way. This approach is completely opposite to an older but still present philosophy of life that would say: "offer it up" or "I am offering this suffering for…" Among the signs of

[148] Song, *Human Genetics*, 56.

this lack of tolerance for suffering is the number of people self-medicating and consuming all sorts of drugs and other substances.

In my ministry, I personally witnessed an increased number of young people cutting themselves, attempting or committing suicide as their way to deal with their struggles and long term issues that make them suffer. Many of these young men and women are not learning how to face psychologically and spiritually their own sufferings in a healthy way. As they become adults, we can only wonder will they be able to cope with the long-term illness or handicap of their child.

The *Catechism of the Catholic Church* states in a very simple way a very powerful reality, "The way of perfection passes by way of the Cross."[149] In the Gospel of Matthew 16:24, Jesus told his listeners that in order to follow him, they had to pick up their cross. A phrase from one of Archbishop Fulton Sheen's Easter homilies, that has been quoted often, reminds us that "unless there is a Good Friday in her *(the Church)* life, there will never be an Easter Sunday."[150] It is critical to understand that what Jesus, the *Catechism*, and Archbishop Sheen are saying does not mean that it is acceptable or even good to be victims of injustice and abuse. These and all other forms of violence against the person cannot be seen as the cross that Christ wants them to carry in order to reach the glory of Easter. What these voices are trying to teach us is that in the Christian journey towards perfection there will be some suffering. And as mentioned before, suffering can be caused by the personal physical struggles or by sharing the struggles of someone we love. Even athletes and trainers acknowledge that there is 'no pain, no gain' in order to become better athletes. Doctors and patients recognize that the physical pain during the recovery from a surgery and the physical therapy are part of improving one's health. By the same token,

[149] *CCC*, no. 2015.
[150] Archbishop Fulton J. Sheen, "The Divine Romance: Dying and Behold We Live," last accessed 11/4/2019. https://www.catholicculture.org/culture/library/view.cfm?recnum=3787.

if the personal target in life is to achieve true perfection, then some level of suffering is unavoidable and learning how to face one's struggles is necessary. Similar to the trainee or the patient, some days this is not exactly what people want to hear!

If experiencing some suffering is part of the spiritual road to perfection, is there a place for fear in that journey? Clearly, people fear the possibility of becoming ill; they fear pain, suffering, seeing their loved one suffer, and ultimately, many fear facing their own death. It is impossible not to have some level of fear. Being afraid is not necessarily a sign of lack of faith or trust in God. Jesus himself experienced some fear that night at the Mount of Olives as the crushing passion was about to begin. "He took with him Peter, James and John, and began to be troubled and distressed. Then he said to them, 'My soul is sorrowful even to death.'"[151] Jesus looked for comfort and strength in prayer, and turned to God and to his loved ones, his friends. The challenge for him and for all of us is to avoid or at least control despair, anxiety, anger, doubt, resentment or all of them combined. The challenging task in those moments of fear is to trust and hope that God will provide the comfort and grace needed to face any form of suffering, even the scariest of all: death. Saint Paul wrote to the Corinthians "Death is swallowed up in victory."[152] And he continued, "But thanks be to God who gives us the victory through our Lord Jesus Christ. Therefore, my beloved brothers, be firm, steadfast, always fully devoted to the work of the Lord, knowing that in the Lord your labor is not in vain."[153] Within Christian spirituality, some type of fear might have its proper place.[154] Some theologians call it *religious fear*,[155] by stressing how the conscience awakens and desires to be faithful to God out of love

[151] Mark 14:33-34a.
[152] 1 Cor 15:54.
[153] 1 Cor 15:57-58.
[154] See *CCC*, no. 1830, which is based on Isa 11:2.
[155] See Desiderius Erasmus, "Preparing for death," trans. John N. Grant, in *Spiritualia and Pastoralia*, *Collected Works of Erasmus*, 70, ed. John W. O'Malley (Toronto: University of Toronto Press, 1998), 428.

and reverence. Ultimately, according to the Gospels, the only thing we should be completely afraid of is *spiritual death*,[156] that which kills the soul[157] and pushes us away from the love that God has for us.

Beyond health issues

Individuals, families, scientists, and communities have to deal with health or challenging health conditions. What happens when we decide what we can or cannot bear?

Every parent desires that their children be born healthy and that they grow up with the least challenges and disadvantages as possible. Most parents, if they had the opportunity, would remove all the obstacles that could harm or affect their children. These are noble intentions and there is nothing wrong with this good will towards one's own child or, as a matter of fact, towards any child. Parents search for the best schools, programs, and activities to enhance the opportunities of development of their children. Even in developing countries, parents will undergo huge sacrifices so that their children may receive education or even something more essential, like healthy food. Therefore, it is not surprising that given the opportunity to improve the odds of their children, parents might consider certain genetic changes. As mentioned earlier, there are changes related to health, but there are other modifications considered to be enhancements or choices. All through the pregnancy, after birth and until their independence, parents are constantly making choices on behalf of their children. Some will argue that if parents are careful in choosing which schools their children will attend, and provide all other forms of assistance such as tutors and computers to improve the chances of obtaining a better education,

[156] See Erasmus, "Preparing for death," 412.
[157] Matt 10:28: "Jesus said, 'And do not be afraid of those who kill the body but cannot kill the soul; rather, be afraid of the one who can destroy both soul and body in Gehenna.'"

then why not try to enhance the genes that impact their intelligence?[158] The argument made by parents and scientists can be summarized as: If the final result is good for the child and it is done with good intentions, then it should be acceptable to proceed with the enhancements.

It is true that so many things are already being done to improve the physical, intellectual, and emotional well-being of the child. However, prudence is needed to determine how far parents and scientists should be allowed to go in order to fulfill the desire of having a 'perfect' baby, a 'perfect' child. Quite often there are too many variables impacting the development and growth of a child. It is naïve to believe that everything will be under control by relying simply on genetic modification. The best proof of this uncertainty is the everyday experience of rearing children. How often parents cannot explain why, after following the same education and discipline, their children may turn out to be so different from each other. It would be naïve for parents to believe that their children will grow up and be 'perfect' because they modified their genetic sequence. It is impossible to guarantee that some of the enhancements made to the genes of an embryo will manifest themselves in the child and adult as they develop.

What is normal, average, and natural

Another important aspect to address is defining the parameters of what is normal, average, and natural, when the use of such terms is referring to a range of qualities that are found in the members of a society and therefore are considered acceptable. For example, there is not an exact height for a man or woman, but a range where the majority of people can be found. Therefore, when someone is outside the range by being too short or too tall, some within the general population consider this person to be somehow defective. The line between being normal or not is more clearly drawn when the differences are the result of diseases caused by a

[158] See Song, *Human Genetics*, 59.

virus, bacteria, or exposure to unhealthy materials in the environment (i.e., pollutants, asbestos, lead, and radiations).

The other term we should consider is natural, which defines what followed the course of nature without intervention. As examples, in the twenty-first century, in the developed countries, there is a growing number of consumers who are longing for 'natural' foods and expecting mothers want to have their babies at home with a midwife and without any medication. This desire to avoid genetically modified foods or avoiding food that has been exposed to chemicals, or give birth naturally as a way to return to what is simple, healthy, and unspoiled, clashes with a whole different approach within society. While some want everything to be as natural as possible, others have their bodies bombarded with more medications and chemical substances than ever before; natural phenomena like procreation are replaced by artificial procreation in the case of infertile and sterile couples; and there is the desire to modify and manipulate the human genetic makeup. It is interesting to observe a new social trend: everything that is considered organic, and therefore natural, is considered to be better and healthier. Ironically, at the same time, in other circles, the desire for what is 'completely natural' is perceived as less important and it is compromised particularly in what concerns the creation of human life and the modification of the human body.

People are already experiencing different levels of enhancements: short-term (energy drink), long-term (corrective surgery), putting their own effort (practicing and training for sports), being a passive recipient (wearing teeth braces).[159] These diverse types of enhancements are important. Within society, and this includes family members, people show great pride when an individual works hard and extensively to improve his or her physical condition. The opposite is also true; there is shame and even negative consequences (so far) when athletes artificially

[159] See National Academy, *Human Genome Editing,* 140.

improve their muscle mass. This tug of war is exemplified when considering the reactions of the media, the fans, and other players when a baseball player in the Major League Baseball was suspended for using performance enhancement drugs.[160]

The term enhancement is used for a spectrum of scenarios in which a person is improving the present condition. For an individual born with a condition that most people in society consider it to be negative, to be enhanced could mean overcoming or being healed from the present status and having a 'normal' life. For a person considered to be already healthy, enhancement might be improving a quality that places ahead or above the average population. In the case of genetic editing or any other treatment, this contrast between restoring health and improving beyond the average should be taken under account. There is a critical difference between helping a person reach the level of 'normal' and 'average', and improving one's capacity above the average or norm.[161]

Another issue to be considered is who determines what is a disease, what is not 'normal' and needs to be corrected. As noted in history, there was a time when being a homosexual or a criminal was considered an illness and scientists tried to correct them therapeutically, obviously without success.[162] It is impossible to remove completely the personal and cultural bias of those making decisions of what should be considered an unacceptable condition, and therefore, that what should be treated in order to overcome it.

In discussing the contrast between healing and enhancement procedures, there is nowadays a third area to be considered: *preventive medicine*. Clearly, the procedures or

[160] "Saturday afternoon (September 7, 2019) Major League Baseball announced Minnesota Twins right-hander Michael Pineda has been suspended 60 games after testing positive for Hydrochlorothiazide, a diuretic and common masking agent for performance-enhancing drugs. The suspension begins immediately." See https://www.cbssports.com/mlb/news/twins-michael-pineda-suspended-60-games-after-testing-positive-for-performance-enhancing-drug-masking-agent/.
[161] See National Academy, *Human Genome Editing*, 145.
[162] See ibid., 148.

treatments used in preventive medicine are neither healing an illness nor setting the person above the rest, but they aim to protect their health and well-being. The most classic and common preventive medicine already practiced is immunization, vaccinating the person from an early age.[163] As with the vaccines, many preventive medicines have proven to be beneficial for the quality of life of individuals and communities. The concern is if preventive medicine is only available in certain countries and accessible to specific groups of people, then it can enhance the life of a segment of the population over another.

As described earlier, there are many ways of understanding and evaluating an enhancement. It could be considered as a negative practice or option when it "confers a social advantage beyond that which an individual possesses by fate or through personal effort, and that does not benefit the rest of society…"[164] In other words, serious questions and concerns need to be raised if the person that will be enhanced is not affected by any disease and, at the same time, the purpose is to place that person above others. This would create an elite including only a few chosen ones, neither because of natural development nor as a result of individual's personal labor.

Other concerns with enhancements

A first important concern is how children are treated. If a child has been enhanced, automatically the parents and other people in society will consider the other children as lacking those 'great qualities' or 'perfection'. Some may argue that this comparison may not happen at all. The only way to have a glimpse of the future is to observe present practices. Parents compare, and in some cases brag, about the levels of competence of their children, let it be

[163] See National Academy, *Human Genome Editing*, 147.
[164] Ibid., 150.

academically or athletically. Of course, it is hard not to brag about the excellent grades of a son in high school and the amazing performance of a daughter in a basketball game. The danger is when the average child in the classroom or on the court is looked down as inferior, as if they had a disability because they are not able to perform as well. It is not just in movies that the over-achievers have undermining looks and degrading comments towards those children who performed differently.

In a hypothetical future with enhanced children, there could also be negative reactions towards parents who cannot afford to enhance their child or choose not to do so.[165] Such a choice might suggest to some that those parents do not care about the well being of their children. An elite mindset and negative reactions can already be seen towards families who cannot afford the expensive sports camps or private schools with accelerated academic programs. Working in an expensive private high school, I witnessed tensions between those who can afford the full tuition and those who depend on scholarships. Nothing new; these are the same old frictions between those who have and those who have not. If genetic enhancement will be used on people, it seems that all members of society will have to consciously take upon themselves the task of avoiding any pejorative attitude, discrimination, and pity towards the children who will not be enhanced.

Chance or choice

If genetic editing is applied to humans for enhancements, there would be a move *from chance to choice*. What would be the impact on that particular genetically enhanced child, but also on the dignity of children in general, if children could be enhanced? Humans have a wide range of qualities and abilities. Part of the richness of humanity is the mingling and interaction

[165] See Cahill, *Theological Bioethics*, 214.

between all these possibilities: different heights, color of skin, muscle strength and abilities for math, music and sports. The possibility of being made or tampered with, not naturally conceived and received, can lead to objectification. The child can then become the product of the parents' making and design, and not necessarily the unconditional and generous embodiment of their love.[166] Even if an enhanced child is objectified, he or she will not lose human dignity. Moreover, if scientists were able to perform multiple enhancements to the embryo, it will be interesting to see how the family, and the people working in the lab, see this child.

Some people may argue that the ability to take control of what is best for one's children, by making these choices and having the freedom to do so, actually means honoring our humanness. Parents and scientists are using their gifts, talents, and possibilities. Such a statement is true for those who can make decisions. They are responding to the call to be creative, to use their knowledge and resources to improve their descendants. However, in arguing in favor of the right and 'blessed' opportunity to choose to enhance, it should be noticed that those being impacted the most (the children) have no say about those changes; they have no freedom to choose.[167]

Governance

As mentioned in Chapter One, when treating somatic diseases the United States Food and Drug Administration would regulate genetic editing, as well as the Recombinant DNA Advisory Committee, institutional biosafety committees, institutional review boards, and the US legislature.[168] A concern with all medications and treatments is that physicians have a certain freedom of judgment that allows them to use medications and/or treatments in other

[166] See National Academy, *Human Genome Editing*, 157.
[167] See ibid., 158.
[168] See ibid., 151.

circumstances beyond the original conditions for which they were intended. Therefore, there is a possibility that physicians could use this freedom or flexibility to recommend genetic editing for enhancements instead of treating an illness.

From a social justice perspective, it is worrisome the amount of financial resources invested in pursuing enhancement. The resources that could be used to enhance the body of someone who is actually healthy, could be used to benefit so many in the world who lack the basic medical treatments. This way of reflecting about health may be a pressing concern for some governmental agencies, but less when research and applications are privately funded.

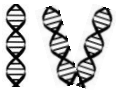
The virtue of love

I conclude this chapter on enhancement by referring to the virtue of love. The apostle Paul wrote to the Corinthians that love should not be jealous or rude, but patient, kind and should bear all things (see 1 Cor 13). This God-given virtue empowers us to love one another, even our enemies, to love those who hurt us, those who are imperfect, those who God has entrusted to our care and protection. In some ways, many genetic and scientific advances can threaten love. How is that possible? Every mother and father is called to love their children, to accept them for who they are, with their strengths and weaknesses, character flaws, unique traits, infirmities, and physical disabilities. Love cannot and should not be conditioned to what the parents expect their children to become as they grow, or what the parents designed them to be. Love will assist parents to care for their children so that they can overcome or deal with their limitations. Love will also grant the parents what they need to face the suffering connected with their children's

struggles. As Paul says, "For we know partially and we prophesy partially, but when the perfect comes, the partial will pass away."[169] If it is perfection that the person desires, love is essential.

[169] 1 Cor 13:9-10.

Chapter



Some spiritual tools for discerning gene editing

In our faith tradition, Christians are encouraged to discern when facing daily life experiences, but especially in those critical moments when they need to make life-changing decisions. Whether society should engage in genetic editing, if it is the best healing option for my family or myself, if it respects human dignity and rights: these are some of the questions that require an ongoing discernment. Without any doubt, the actions and words of Jesus can and should enlighten this process.

Jesus, the exemplar

Scripture shows how often Jesus went to pray, especially as he was about to face difficult circumstances. As mentioned in Chapter Three, the night of his betrayal he went to pray in the garden at Gethsemane. He even asked his apostles to pray with him, but they were unable to keep up. Did he get discouraged? It seems like he was frustrated with them, but that was no

excuse to stop praying. He kept going back over and over to pray (Matt 26:36-44). Prayer offered him the strength and peace he needed. In every discernment, it is necessary to increase our personal prayer and, at the same time, to invite others to join us by praying for us and with us.

All through his life and ministry, Jesus showed a profound compassion for others. This compassion was manifested to the very end of his life: when he washed the feet of his disciples (John 13:1-14), gave his body and blood at the Last Supper for spiritual nourishment (Matt 26:26-28), healed a wounded persecutor (Luke 22:50-51) and, from the pulpit of the cross, he forgave the crowd and the repentant thief: "Amen, I say to you, today you will be with me in Paradise" (Luke 23:43). In the midst of his pain, Jesus made sure that his widowed mother would be protected and cared for by his friend and faithful disciple, John.[170] During his passion and death, Jesus was not only compassionate, but he also welcomed compassion from others. He allowed Simon the Cyrenian to assist him with carrying the cross (Matt 27:32). Even after his death, he relied on the kindness of others to provide the proper burial, among them Joseph of Arimathea who "taking the body, wrapped it in clean linen and laid it in his new tomb that he had hewn in the rock" (Matt 27:59-60a). How beautiful and powerful it is to show compassion to those who need it, and to be humble enough to receive it from others when we are those in need.

As a teacher, Jesus provided a prime example of solidarity and fidelity with those who were suffering. The Gospel stories about the death of someone else and how Jesus reacted may cause some confusion. When Jairus (Mark 5:35-43), the widow of Nain (Luke 7:11-16), and

[170] John 19:25-27: "Standing by the cross of Jesus were his mother and his mother's sister, Mary the wife of Clopas, and Mary of Magdala. When Jesus saw his mother and the disciple there whom he loved, he said to his mother, 'Woman, behold, your son.' Then he said to the disciple, 'Behold, your mother.' And from that hour the disciple took her into his home."

Martha and Mary (John 11:1-44), lost his daughter, her son and their brother respectively, Jesus brought those dead back to life. It may give to some readers the impression that there is something wrong with dying. To add to the confusion, why did Jesus cry before the tomb of Lazarus? What can we learn from Jesus in regards to our response to suffering and death of others? The reactions of Jesus restoring life and crying were not a result of doubting the goodness of the afterlife, seeing death as an evil that must be avoided at all cost, or incapacity to deal with the death of a loved one. In these and other cases, Jesus is showing solidarity and fidelity[171] with those who are mourning. If fidelity is that virtue by which relationships are fostered by responding to the needs of others, then these acts of healing and bringing back to life can be seen as more of a compassionate response to the mourners who are living, than solely to the people who were dead. This is a reminder that the family and caregivers of those who are ill or with a disability also need care and support. As they mourn due to the sufferings of their loved ones, they need spiritual, emotional, material, relational, and physical support.

Without any doubt, the crowds were highly impressed with Jesus' healing actions, all of which showed compassion, solidarity, and fidelity. Besides being sick, most of them were also outcast, rejected by the society and even their own family. When he healed the ten men with leprosy (Luke 17:11-19), the woman suffering with hemorrhages for twelve years (Mark 5:25-34), and many other sick people, he restored their health but also their rightful place in society. As the Word made flesh, Jesus reveals to us God's desire to heal us. Therefore, there is a Christ-like attitude and a God-like task in trying to heal others from their illnesses, to rescue them from pain and isolation, and to restore them to a fullness of life.

Throughout the Gospels, Jesus shows how healings are signs that the reign of God is at hand. What does that imply? First and foremost, anyone who is "broken off from friends,

[171] See James Keenan, "Proposing Cardinal Virtues," *Theological Studies* 56, no. 4 (1995), 725.

family and God"[172] due to an illness should experience, through the act of healing, reconciliation with all of the above. This reconciling healing is not limited to the individual who is cured but also impacts the community. The family and friends also experience this healing and reconciliation with each other and with the rest of society. As we have seen many times, the isolation and marginalization is not limited to the person who is sick. Quite often the family members who function as caregivers are isolated by their own choice when there is a sense of shame and embarrassment due to their ill relative, or because other members of the community have 'pushed them away.' (When I was growing up, I saw this happen too often when a family had a child with Down syndrome.) The hope is that by restoring the physical health of the individual, that person and their entire family are restored within the community.

Second, the healing must go beyond the fact of no longer being sick. There has to be a 'follow up' of service, which implies caring for others as or better than how they were cared for, and as a way of showing gratitude to God.[173]

Third, if healing and reconciliation are part of the reign of God, then everyone should be part of the action. As the first disciples, we are all called to the best of our ability to restore as many people as possible. And if by any chance we are unable to be effective in the healing process itself, then to be at least supportive of those who can. Following the example of Jesus, then we must remove "people from positions of dependence and marginalization… (freeing) them not only from bodily misery but also from the social stigmas that ostracized them."[174]

At different times in the Gospel, Jesus foreworns about false prophets; therefore, it is necessary to recognize the 'false healings and healers.' These are the ones who do not work

[172] Terrence W. Tilley, *The Disciples' Jesus: Christology as Reconciling Practice* (Maryknoll, NY: Orbis Books, 2008), 142.
[173] See ibid., 143.
[174] Ibid., 145-146.

towards the realization of God's reign.[175] This indifference, or even sometimes opposition, can be determined when there is an absence of joy, because there was no reconciliation and restoration with society.[176] If the focus is just to cure a disease, and not caring for the person, then the task is half done.[177] We are in a time in the USA when the insurance companies rule and dictate the care that is offered to those insured, and many times with a strong for-profit approach. Hence, many with actual health issues are left unattended, while often efforts and resources are placed on cosmetic issues for some.[178] With the possibility of genetic editing, what will happen if enhancements are more profitable than healing somatic illnesses?

Jesus believed that God was there, in place and time, when he was about to endure his passion and death; and trusted that God would carry him through it. This trust gave him the freedom to surrender any control and to allow others to take over his physical life out of love. This became obvious when he did not run away before or during the arrest.[179] Trusting God was accompanied by hope in the afterlife. He knew that after his agony and death God would receive him and entrust to him the gift of the resurrection.[180] Maybe this is one of the toughest challenges: to let go of our control; to surrender and acknowledge that sometimes there is nothing we can do to change what is happening to us or to others.

The challenge of Jesus

One of the difficulties that people have nowadays, when they compare their sufferings with Jesus', is that what they are going through seems meaningless in contrast to the redemptive

[175] See Tilley, *The Disciple's Jesus,* 147.
[176] See ibid., 146.
[177] See ibid., 148.
[178] See ibid., 149.
[179] See Christopher P. Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well* (Lanham, MD: Rowman & Littlefield, 2004), 105.
[180] See ibid., 109.

value of the death of Jesus.[181] If "the suffering of Jesus is understood as his bearing the sins of humanity,"[182] then it is true that we are definitely unable to compare with his purpose and effects. But it is also true that we are called to share in the sufferings of Christ.[183] His suffering can be considered "as an ingredient in the process by which followers become conformed to his image."[184]

Another challenge is Job's experience in the Old Testament, in which he lacks understanding as to why he has to suffer. Job is not questioning God's existence. Like many other people, he questions why does she or he or I have to suffer, especially when we are under the impression of being good and faithful people. What is presupposed is that pain and suffering are reserved for those who have done wrong in life. With the book of Job, the Judeo-Christian tradition begins to discuss "that suffering is natural to humans simply because they are humans,"[185] not necessarily as a punishment for wrongdoing. The new Job–Jesus–became the ultimate example to discredit this former (although sometimes still present) mentality. Even Pontius Pilate publicly recognized Jesus' innocence before condemning him to death (John 19:4). At the same time, Jesus gives witness that "the experience of pain is not optional,"[186] not for him and not for any of us. And he also teaches the importance of being humble when the time comes to face suffering. First, we all need humility to recognize that our sufferings and death do not and cannot fully compare in purpose to Christ's. Second, humility allows individuals to refrain from making comparisons between one another, using a measuring tool that directly correlates the behavior of a person with their level of suffering. Having an illness or

[181] See Vogt, *Patience, Compassion, Hope,* 117.
[182] Luke Timothy Johnson, *The Revelatory Body: Theology as Inductive Art* (Grand Rapids, MI: William B. Eerdmans, 2015), 114.
[183] See ibid., 113.
[184] Ibid., 114.
[185] Ibid., 111.
[186] Ibid., 107

having a child with an inherited condition should not be used as a moral "measuring stick" to determine whether the person or the parents have been moral or immoral. Lastly, as with so many other things in life, humility is necessary in order to recognize that many times there is no clear answer or reason to certain illnesses, sufferings or deaths. Our bodies are fragile.

Sanctity of the body

God recognizes that both the whole creation and human beings within it are very good.[187] Men and women are created in the image and likeness of God,[188] and this creation includes the body. One may question, if the human body was made good, and there is beauty in that goodness, then why is there such a great demand or desire to change one's body? The changes can be superfluous or temporary (hair color), long lasting (tattoos), and deeply transforming (any form of genetic modification). There are too many reasons behind those changes. Among the positive ones, the most obvious is that there is a natural desire to improve. Among the reasons that should concern us, one is when some people are motivated by lack of love for themselves. What a painful reality, when people on their own or due to rejection from others, dislike or even hate who they are. As family, friends, and faith communities, how important it is that we support each other in loving ourselves, no matter what illnesses, conditions or physical characteristics we have.

Unfortunately, dualism between body and spirit is still lingering in some minds. Moreover, there are people and communities that view "the body as a disposable and not entirely worthy package for spirit."[189] When this mentality prevails, the result is that the spirit is the only thing that is seen as made in the image of God and the body is completely excluded. As a result,

[187] See Gen 1:31.
[188] See Gen 1:26.
[189] Johnson, *The Revelatory Body,* 65.

some become indifferent to their body or even reject it. But the account of creation in Genesis does not "make a divide between human spirit and body, or attribute image only to spirit."[190] When there seems to be no connection between the human body and God, it might be easier to randomly modify the body. When there is a Christian understanding of the body, then there is a clear appreciation of its dignity, and being part of the body of Christ and temple of the Spirit.[191] With this knowledge in mind, the random desires to modify or edit the body can be seen almost as a "desecration of the body."[192] Therefore, as individuals and as communities, we all need to move towards a greater appreciation of the human body and its role in our spiritual growth, and avoid seeing it as an obstacle. Luke T. Johnson summarizes the rightful role of the body by saying that "the human body not only can reveal God, it is the privileged medium of divine self-disclosure."[193] Our bodies and senses have been among the most effective ways in which God self-reveals. And God's self-revelation to us never stops, and our challenge to keep learning more about God and to love God in ourselves, others, and in creation, does not stop either.

Many people believe that science and theology are nemesis in the search of truth, when actually science has, can, and should join theology's task of discerning God's revelation and will. If scientific knowledge and discoveries are part of the culture of a people, it has been obvious in our Judeo-Christian beliefs, as in all other religions, the impact that culture has on those beliefs.[194] The opposite is also true: religious beliefs have a great impact on the culture of a community, and that includes their scientific interpretations. It is important to acknowledge that scientific developments in regards to the body impacted our theology and spirituality. For

[190] Johnson, *The Revelatory Body*, 54.
[191] See CCC, no. 364.
[192] Tim Drake, "Tattoo Taboos – Catholics Debate the Morality of Body Art," *National Catholic Register* 84, no. 35 (September 7, 2008), 2.
[193] Johnson, *The Revelatory Body,* 57.
[194] See Robert John Russell, "The Contributions of the Natural Sciences to the Academic Discipline of Christian Spirituality," in *Exploring Christian Spirituality: Essays in Honor of Sandra M. Schneiders, IHM*, ed. Bruce H. Lescher and Elizabeth Liebert, SNJM (Mahwah, NJ: Paulist Press, 2006), 123.

example, in biblical times most illnesses were seen quite often as a punishment from God, until later on when viruses and bacteria, and their impact on the body, were discovered. As late as the twentieth-century, some ethnical groups were seen as inferior and imperfect, until genetic information among other things, confirmed our equality and similarities. What remains to be discovered about our bodies is the task of the current and future generation. As with our ancestors, there are things we know about our bodies that maybe two hundred, or just twenty years from now, will prove our present knowledge as erroneous.

How do we consider the interaction between science and theology? Robert J. Russell presents Ian G. Barbour's proposed four main dynamics: conflict, independence, dialogue, and interaction.[195] *Conflict* is mostly seen in scientific atheism: everything can be explained scientifically and there is no space for God. Some religious groups took a defensive (and sometimes offensive) position. Another model is when science and religion are seen as "totally *independent* of each other;"[196] each one focused on their own field of studies. With *dialogue*, there is an acknowledgement of the historical contribution by which they fostered each other, and also the role of theology to try to explain questions that "point beyond science."[197] Lastly, *interaction* provides for the opportunity "of genuine and mutual two-way exchange and fruitful growth in our theological and scientific understanding of the universe and humanity."[198] I agree with Russell and Barbour that science and theology cannot be kept apart by conflict or independence. Science and theology should be engaged in dialogue and interaction. This

[195] See Russell, "The Contributions," 125-131.
[196] Ibid., 126.
[197] Ibid., 127.
[198] Ibid., 129.

implies that theology must take seriously the scientific discoveries, and that science cannot discard theological reflections and assumptions which cannot be empirically explained.[199]

With the previous discussion about God's revelation and the sanctity of the body in mind, we should rephrase what we asked throughout these chapters. Besides asking what are the reasons or purposes for genetic editing, we should now also add what does genetic editing reveal about our bodies, about our *imago Dei*, and about God. Is the goal to heal, to carry on God's creative actions, to make that reign of God more present in our midst, or to 'just' modify the body? In regards to healing, the *Catechism of the Catholic Church* affirms: "Life and physical health are precious gifts entrusted to us by God. We must take reasonable care of them, taking into account the needs of others and the common good."[200] Because they are "precious gifts" there is an obligation to look after the well-being of the person. There is a call to use our wisdom, technology, and natural resources to protect and improve the health of those who are sick. This call to duty is limited by justice. The Church clearly acknowledges that care should be "reasonable;" it cannot favor a small segment of society by consuming an excessive amount of resources available in order to help them. She expects the entire community to keep in mind the "needs of others," not to focus on benefiting only a few people.

[199] See Russell, "The Contributions," 129.
[200] *CCC*, no. 2288.

Conclusion

How is genetic editing leading us closer to God? Everything we do in our earthly journey in one way or another should improve or enhance our lives in order to make us wholesome. Based on our study, being wholesome should include among many things: overcoming illnesses, being restored within society, the ability to recognize God's presence and creative work, using God's gifts and acknowledging that they are God-given, and seeing the goodness in the whole creation. It is important that all these things are happening, so that when we move forward with genetic editing, because it seems already occurring, this editing should uphold the innate goodness by which every individual is created.

Hopefully, people discerning if they should engage in genetic editing research and clinical trials will find in their ecclesial communities a place and opportunity to have a conversation about these issues. Pastoral leaders should be ready to support the procedures that foster health improvements and, at the same time, maintain the dignity of the person. Moreover, they should be able to challenge those treatments that reduce the person (adult, child, or embryo) to an object that is being used mainly for the benefit of researchers and private companies fostering the research.

Saint Thomas Aquinas made an interesting distinction between *studiositas* (studiousness) versus *curiositas* (curiosity). According to him, *studiositas* is positive desire for knowledge and *curiositas* is negative desire for knowledge.[201] When dealing with genetic editing, Aquinas' negative knowledge applies if, for example, the main motivation behind genetic discoveries and experimentation is financial enrichment. Probably, Aquinas would not suggest to stop research on genetic editing in some cases, but what he would ask is to make sure that scientists are not 'fooling around' or tampering with the human body just to see what they can find or discover.

At every stage of research, during clinical trials, and in the case of future implementations of genetic editing, it is critical to foster a society that recognizes the dignity of every person–even when ill or with a disability. This includes treating the person with respect and love, and finding the best ways to address their condition. The goal is to avoid ever looking down at persons as if they have worthless lives due to their situation or condition. Charity is always needed even in the case of genetic editing. It is necessary to promote love for one's neighbor, and as Pope Benedict XVI said, more than a neighbor, our brothers.[202] For Christians, the ultimate goal is to build the kingdom of heaven here on earth. Therefore, we need look at what is happening in laboratories and hospitals, and the reasons that justify what is being done, to see if it responds to an authentic and loving desire to improve, heal, and serve *all* peoples, our brothers and sisters.

If we look at Jesus' ministry, we can see how God wants us healthy, well fed, and joyful. It is very obvious that God provided men and women with great wisdom, and nature with amazing resources. It would be a failure and betrayal to the vocation of scientists, researchers, and anyone else in the medical field if we did not use our God-given gifts and talents to do the

[201] See Messer, *Respecting Life: Theology and Bioethics*, 160. Makes reference to Thomas Aquinas, *Summa Theologiae*, II-II, q. 166, q. 167.
[202] See Benedict XVI, *Caritas in veritate,* no. 19.

best we could to heal someone. The call to heal is beautiful. But even these healing vocations have an essential moral limitation: the healing of one cannot be achieved by hurting another.

Two basic tasks remain at hand: finding cures for illnesses and supporting individuals as they deal with illnesses (as patient or caregiver). In both tasks, it is important to cultivate the virtues of patience, charity, and humility. In spite of the number of scientists involved in medical research, we are still facing many illnesses. How to cope with these health struggles? If we believe in the wisdom of Scripture, as caregivers, Jesus reminds us to love another as he has loved us and that there is no greater love than to actually give one's life for someone else–after careful discernment. In caring for someone we respond to Christ's call to divine love. For Terrence W. Tilley, "We have come to take the practice of medicine as 'curing diseases' and 'beating death' rather than 'caring for people.'"[203] All those who are providing and receiving health care in homes, hospitals, and nursing homes should experience support and even love from family, friends, coworkers, and especially from faith communities.

Both in the case of caregivers and the sick, Jesus invites all those who are burdened or tired to come to him. He offers relief. Sometimes we forget this promise and believe that we have no help. But this would be "egocentric ambition to secure their health and improve their quality of life by relying exclusively on their own power, wisdom, and technical means."[204] In either scenario, whether it is struggling with an illness or finding a cure in a lab, what a difference when Christ is walking along!

Throughout this research, one challenge was to adapt and implement theological arguments to address new scientific advancements. As Christians, it is easier to grasp and explain to someone else the morality of an issue when there is a clear biblical reference,

[203] Tilley, *The Disciples' Jesus*, 148.
[204] See Koios, "Theological Anthropology," 187.

especially if it refers to Jesus. I am convinced that it is a challenge for pastoral staff and moral theologians to respond with the same conviction and authority to everything that is happening in the realm of new biological discoveries, and to faithfully articulate one's arguments.

When I asked the children of my parish what they knew about genetic mutations, the answers I got were: humans could fly, and could have extraordinary strength. They sounded excited about the 'super powers' obtained by the characters in movies like *X-Men*, which is an imaginary world with a growing number of mutated humans. In the real world, most human genetic mutations cause illnesses, and there is nothing exciting about that. Genetic editing can be an opportunity to correct the genetic mutations causing these illnesses. At these early stages, CRISPR/Cas9 seems to be financially affordable for the upper class and maybe even the middle class of society. Maybe in a few years, like other vaccines and medications in the past, it could become more accessible for everyone. It seems like there will be ways of engaging in some human trials without disregarding the needed respect for human dignity and for one's identity. Unfortunately, some of the human trials will involve using embryos and even discarding some of them, and that will not be applauded or supported by Catholic official teaching.

In summary, Catholic moral teaching supports genetic editing in adults with somatic illnesses, if it can be performed safely and with health benefits for the person. If the modification takes place in the germline, the common concern is that no one knows its impact on future generations. A moratorium has been asked on these experimentations.

At the present time, IVF would be necessary for germline editing. As common as IVF may be, it is not accepted by the Church's Magisterium.

As much as we want ourselves and our loved ones to be healthy and flourish, genetic editing for enhancement is seen with suspicion by researchers and ethicists alike.

I am aware of the ongoing developments in genetic editing. Therefore, by the time you finished reading this paper, something new already happened. With that in mind, I hope and pray this research was a helpful tool to foster theological reflection.

We "participate in the creative power of God
and are called to transform creation
by ordering its many resources toward the dignity and wellbeing of all human beings
and of the human person in his entirety."
Dignitas personae, no. 36

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